

# NHGRI

Evaluation of NHGRI's Genome.Gov: Assessment of User Experience  
and Institute Staff Satisfaction

OE #: 03-129-NHGRI

Completed: January 2004

Prepared by: Lynn Baumeister  
Cirque Interactive, LLC  
301-585-5307  
lynn@cirqueinteractive.com

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## 1. Executive Summary

In the summer of 2002 NHGRI launched a redesign of its website ([www.genome.gov](http://www.genome.gov)), performing a major overhaul on the navigation scheme and the content. As part of that effort, the web team identified internal stakeholders as well as external audience segments, and then designed a site to serve those diverse groups. This report summarizes the results of an evaluation performed in the last quarter of 2003 to determine the effectiveness of the new design and content.

Data for this evaluation was gathered from multiple sources:

- Examination of the site by a usability analyst
- Interviews with internal stakeholders and visitors to the site
- Interviews with external visitors to the site
- Survey responses
- Webmaster queries
- Web site statistics

The full details of the data gathering process are discussed in section 4.2 (Methodology) of this report.

### 1.1 Strengths

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Several elements of the layout and content of the site worked well for visitors.

- **Effective top-level categorization (information hierarchy)**  
The primary sections of the website (RESEARCH, HEALTH, POLICY & ETHICS, EDUCATIONAL RESOURCES, CAREERS AND TRAINING, GRANTS, NEWSROOM, ABOUT NHGRI) are useful categories that help visitors move towards to their specific areas of interest.
- **Helpful annotations**  
The site makes effective use of annotation on links to help visitors make efficient navigation choices.
- **Persistently available navigation and SEARCH**  
The navigation scheme makes it easy for visitors to shift from one section to another as they track down their desired information. Additionally, SEARCH and HOME are consistently placed and available from all pages; this allows lost visitors to retreat back to HOME or to try the SEARCH function at any time.
- **Adherence to web usability principles**  
The site follows common usability guidelines such as using a consistent navigation scheme, naming pages, showing visited links, enhancing readability with headings and bulleted lists, and marking off-site links.
- **Multiple paths to content**  
The site is heavily cross-linked, which provides more than one path to content. Since visitors have different expectations about where to locate their target information, the cross-linking helps the site serve a wider audience range. Additionally, some pages provide alternate views on the same content. For example, the FUNDING OPPORTUNITIES page has two lists of the program announcements, one organized by category, the other organized by program area.

- **Excellent content**

Numerous interviewees, including several who regularly visit other sites serving similar content, noted that the site was easy to navigate, well constructed, and clear. Interviewees involved in outreach and education cited content in the HEALTH, POLICY & ETHICS, and EDUCATIONAL RESOURCES sections as outstanding. One interviewee using materials from these sections said the site contains “some of the best consumer-level content available on the web.”

## 1.2 Weaknesses

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Although the overall design is effective, there are areas that could be improved. Later sections of this report provide details on these problem areas as well as recommendations for addressing the problems. Brief examples are provided to elucidate each problem area.

- **Ineffective content**

Some pages do not meet visitors' needs; they provide less breadth or depth than visitors expect.

- The SPECIFIC GENETIC DISORDERS page is a likely target for many visitors, particularly patients, but only satisfies some since so few disorders are listed and there is no obvious way to learn about disorders not listed on the page.

- **Hidden content**

Some content is difficult to locate, even if a visitor knows that it is there.

- Locating the MINORITY AND SPECIAL POPULATIONS page is problematic. Visitors do not associate the page with the ABOUT NHGRI area (where the MINORITY AND SPECIAL POPULATIONS lives) and the links to it in the other sections of the site are not highly visible.

- **Curation issues**

Several interviewees, both internal and external, noted pages in which the information provided was inaccurate, incomplete, or out of date.

- On the REQUESTS FOR APPLICATIONS page, two RFAs with a May 2003 receipt date are listed.

- **Navigation difficulties**

Although the overall navigation scheme works for visitors, there are aspects that are not consistently effective. Some examples are listed below with full details provided in a later section.

- The SEE ALSO section visually recedes due to the smaller font and pastel background. Several interviewees said that they never noticed (or used) the links in the SEE ALSO section.
- The content in the center section on the Tier-2 pages uses prime screen real estate without helping visitors navigate deeper.

- **Unhelpful search results**

The search engine is not as effective as it could be.

- Searching for “Dr. Collins” produces a long list of Meeting Summaries, but not the THE DIRECTOR’S page.
- Searching for “human genome project” does not list the ABOUT THE HUMAN GENOME PROJECT page, which has a well-written consumer-level introduction.

- **Inconsistencies**

There are minor inconsistencies scattered throughout the site. None of these is a major concern, but taken together they make navigation more difficult.

- Off-site links are not consistently marked.
- Breadcrumbs are inconsistent, and therefore confusing. This is particularly problematic when a page is located through a SEE ALSO link or search results. The breadcrumbs should help visitors understand where a page lives so that it can be easily relocated on subsequent visits.
- Not all links support rollover highlighting.
- In-page jumps are not consistently visually differentiated.

## **1.3 High level Recommendations**

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The recommendations below cover the major points discussed previously. More detailed findings and accompanying recommendations are covered in later sections.

- Rework the content on “disappointing” pages. Consider involving outside resources in the proofing process to help gauge the completeness and suitability of the material.
- Provide more direct and obvious navigation to hidden content. In some cases this may require moving the content to another location.
- Fine-tune the navigation scheme.
  - Make the SEE ALSO section more visually prominent.
  - Rework the content and layout on Tier-2 pages to focus on helping visitors successfully navigate more deeply.
- Address inconsistencies.
  - Match page titles and link text.
  - Mark all off-site links.
  - Show the complete breadcrumb trail, but leave off the current page.
  - Ensure that the breadcrumbs show the page’s home location.
  - Provide rollover highlighting on all active elements of a page.
  - Determine a visual differentiation for in-page jumps and apply it consistently.
- Re-examine the existing curator system. The system must support keeping the content current, complete, and accurate but also focus on constructing pages that help visitors navigate and locate their target information.

## 2. General Findings and Recommendations

This portion of the report covers findings and recommendations for issues that involve multiple sections of the site. Each finding lists both evidence sources (survey results, examination, interview data, etc.) and recommendations for addressing the issue. Findings may also include screen shots or quotations from user data to illustrate points.

Later portions of this report discuss findings and recommendations that are specific to each primary section of the site (RESEARCH, HEALTH, etc.).

### 2.1 Navigation

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Both interviews and survey results support that the general navigation scheme is effective. However there are issues that should be addressed to make it even more efficacious.

#### 2.1.1 The SEE ALSO section is not visually prominent.

Evidence: Interview data.

Discussion: Cross-linking is a powerful means of supporting more than one view of the content. The SEE ALSO section on genome.gov provides such cross-linking. When visitors do not notice it, they are losing an important navigation tool. The reduced contrast between the background color and font color as well as the smaller font size causes some visitors not to notice (or use) the SEE ALSO section.

Recommendation:

- Explore alternate visual treatments that make the SEE ALSO section more noticeable. Also explore variations to the skeleton (banner, search, and primary navigation) on the Tier-2 and Tier-3 pages since the primary navigation on these pages visually recedes and this could be affecting how visitors process the SEE ALSO section below it.

#### 2.1.2 Rollover highlighting is inconsistent.

Evidence: Examination and interview data.

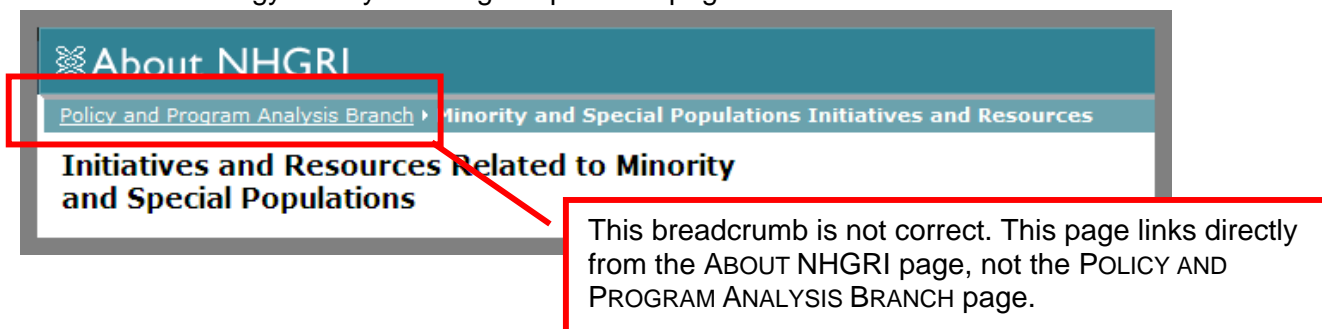
Recommendation:

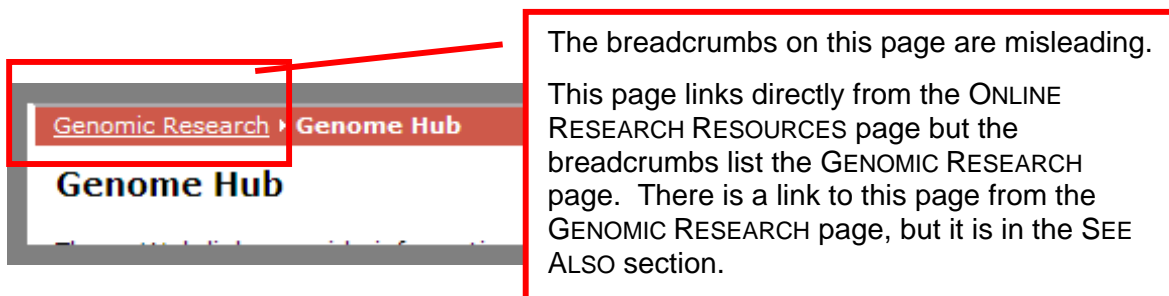
- Provide rollover highlighting on all active page elements. On the HOME page, this includes the Tier-2 bars (RESEARCH, HEALTH, POLICY & ETHICS) as well as the shortcuts listed below them.

#### 2.1.3 Breadcrumbs are incomplete and inconsistent.

Evidence: Examination and interview data.

Discussion: The inconsistent breadcrumbs make it difficult for visitors discovering content through the SEE ALSO navigation or search results to relocate the page on subsequent visits. The current strategy of only showing the previous page in the breadcrumbs is insufficient.





**Recommendation:**

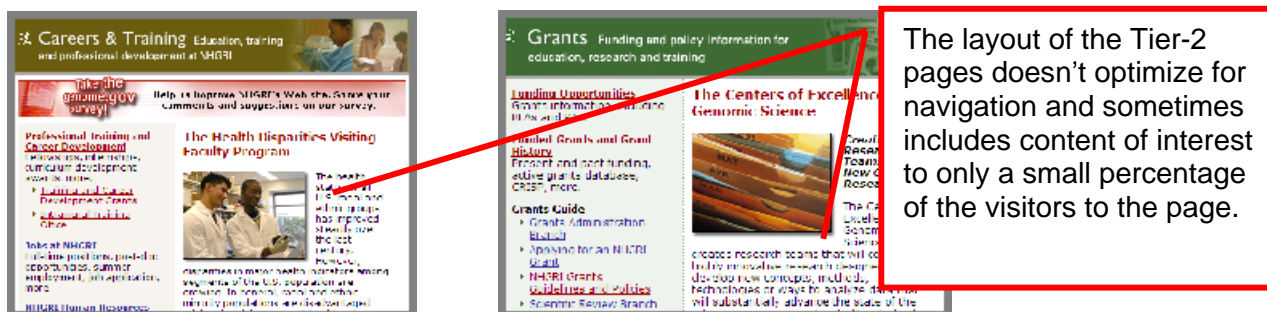
- Show the complete path in the breadcrumbs, not just the previous page.
  - Use abbreviations for page titles (as is done now).
  - Do not include the current page in the breadcrumbs.
- Show the path that leads through primary navigation, not the SEE ALSO navigation. For pages with multiple paths, choose the most intuitive or the shortest path.

#### 2.1.4 Tier-2 pages do not optimize navigation.

Evidence: Examination and interview data.

Discussion: Most visitors landing on Tier-2 pages are still scanning, darting across the page to look for links and keywords that will help them make their next navigation decision. In this mindset, large blocks of text are typically ignored in favor of bulleted lists and headings. During interviews, most visitors glanced briefly at the center section but then concentrated on the options in the left column.

Most Tier-2 pages do an effective job of highlighting links on the left that are likely to be of interest and annotating them to help visitors make effective decisions. However, on some Tier-2 pages the center column is not a good use of prime screen real estate. Visitors are mostly ignoring it, since it does not help them navigate deeper. A better use of the space would be ensuring that both important and popular links are prominent in the top section of the page, since visitors are less likely to scroll on pages they expect to navigate through on their way to their target.



**Recommendation:**

- Consider alternate layouts that focus on helping visitors move closer to their goal while providing visual interest, perhaps with smaller, more scattered graphics, rather than one large dominant visual.
- Avoid chunks of dense text on these pages.

Specific Tier-2 recommendations are included in a later section.



### 2.1.5 Off-site links are not always differentiated.

Evidence: Examination.

Discussion: Some off-site links are clearly marked, but others are not. It is particularly unexpected to find an unmarked off-site link in a list containing other marked off-site links.

**Additional Resources**

- ◆ [Online Bioethics Resources](#)
- ◆ ["A Decade of ELSI Research" Conference: January 16-18, 2000](#)
- ◆ [A Review and Analysis of the ELSI Research Programs at NIH and DOE: Final ERPEG Report \(2000\)](#)
- ◆ [The Belmont Report: On the Department of Health and Human Services site \(1979\)](#)

**Supported Research Programs with Funding Opportunities**

[Sequences, Maps and BAC Libraries](#)  
[Variation](#)  
[Genome Technology](#)  
[Functional Analysis of the Genome](#)  
[Genome Informatics and Computational Biology](#)  
[ELSI Research](#)  
[International HapMap Project](#)  
[Mammalian Gene Collection](#)  
[CEGS](#)  
[The ENCODE Project](#)

This list has:  
An on-site link  
An off-site link (unmarked)  
An on-site link  
An off-site link (marked)

This list has one unmarked off-site link in a list of on-site links.

Recommendation:

- Indicate the host for off-site links

### 2.1.6 In-page jumps are not consistently differentiated.

Evidence: Examination and interview data.

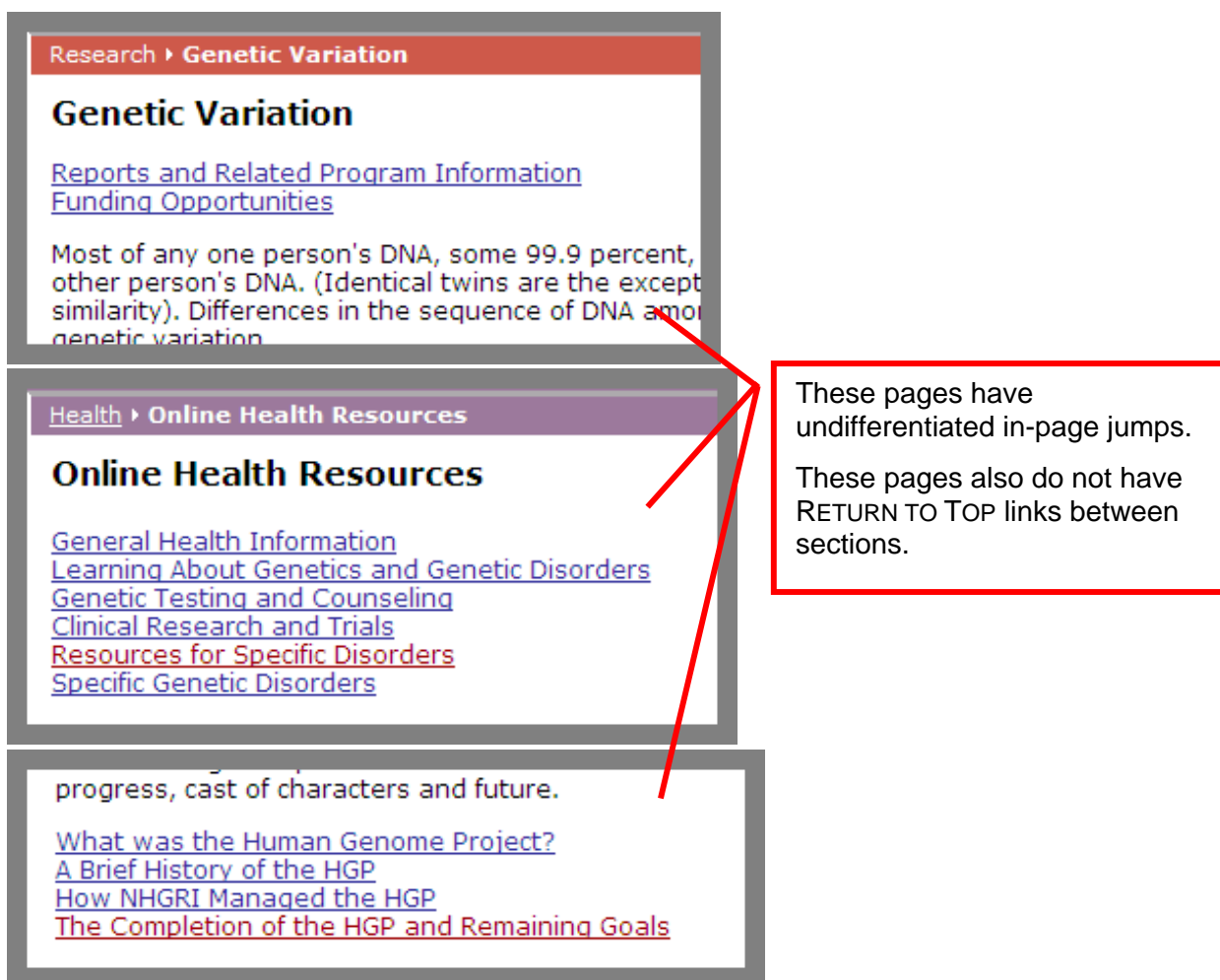
[Health](#) ▶ [Learning About Genetics](#)

**Frequently Asked Questions About Genetics**

- ◆ [What are genetic disorders?](#)
- ◆ [How do I find more information about a specific disease, whether a particular disease has a genetic component?](#)
- ◆ [What is genetic testing?](#)
- ◆ [What information can genetic testing provide?](#)
- ◆ [How should I decide whether to be tested?](#)

These are in-page jumps. But they are not marked.

These in-page jumps are not totally unexpected since many FAQ pages use in-page jumps, but on many other pages they are unexpected.



Recommendation:

- Use a consistent visual treatment for in-page jumps. Use a treatment that differentiates in-page jumps from other links on the page.
- Always supply RETURN TO TOP links between sections.

## 2.2 SEARCH

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The following section discusses the efficacy of the search engine. Some of the issues can be addressed through the interface, but in other cases the search function should be adjusted to ensure that useful results are presented, particularly for common search terms.

### 2.2.1 Search results are not always relevant.

Evidence: Examination and interview data.

Discussion: In some cases the search engine returns useful results. For example, searching for breast cancer yields a variety of helpful results, from funding opportunities to FAQs on breast cancer. But this is not always the case. For example, searching for “McBride” yields no results, and searching for “Dr. McBride” returns a list of meeting summaries, but not a link to Dr. McBride’s research page.

Recommendation:

- Adjust the search engine to return relevant results for common search terms.
- Ensure that common variations on search terms give reasonable results. For example, “Dr. Collins”, “Francis Collins”, and “Dr. Francis Collins” should produce similar results.
- Review the search box entries regularly and consider whether the results for those entries are reasonable and adjust the search mechanism accordingly. For example, the list of search box entries for September 2003 shows “human genome project” as the 6<sup>th</sup> most frequently entered search term but the results for that term do not include the ABOUT THE HUMAN GENOME PROJECT page. That page is a consumer-level introduction to the human genome project and a likely target for visitors.

## 2.2.2 Results are not differentiated.

Evidence: Examination and interview data.

Discussion: The annotations on the search results help visitors determine which results to investigate, but a marker denoting an indication of the section containing the result would also be helpful.

Recommendation:

- Visually differentiate kinds of results. Consider tagging each with the primary section containing the page. For example:

[Model Organisms Update](#)

Progress Made in Sequencing Of Model Organisms' Genomes Chimp, Honeybee Genome Drafts Near Completion; Dog Project Begins  
BETHESDA, Md., May 20, 200...

Search result without a marker  
(how it looks now).

**Newsroom:** [Model Organisms Update](#)

Progress Made in Sequencing Of Model Organisms' Genomes Chimp, Honeybee Genome Drafts Near Completion; Dog Project Begins  
BETHESDA, Md., May 20, 200...

Search result with a marker  
(how it could look).

## 2.3 Site Curatorship

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Visitors expect completeness and accuracy from federal sites, particularly research institutes such as NHGRI. Enough pages were flagged as incomplete or out of date during the interviews to indicate that a different process for curating the content is necessary.

### 2.3.1 Some content is not well curated.

Evidence: Interview data, webmaster queries, and survey responses.

Discussion: Internal interviewees said that they are familiar with the process for getting pages changed, submitting a form to the ASSIGNMENT DESK, and generally noted that the web team was responsive in getting changes posted. Despite this, the curation system does not seem to be working well enough. Several out-of-date or incomplete pages were discussed during the interview process. During the course of an interview that covered an out-of-date or incomplete page, an interviewee might comment that his division or office was in charge of that page, but typically did not know precisely who was charged with curating

the page. On some pages it seemed that curators were adding or updating content (e.g., adding new course listings or program announcements), but not reviewing the existing content to ensure it was still current.

Effective curation is a difficult challenge for any organization maintaining a web site of this size. Resource pages with numerous links (e.g. GENOME HUB, ONLINE HEALTH RESOURCES) can be particularly problematic. Curation on these pages requires both detail work, checking the links and the accompanying annotations on a regular basis, and high-level analysis, considering whether there are resources that should be added or removed from the page.

Part of curation is balancing content push and pull. Content push is information the Institute wants to highlight for visitors (e.g., National DNA Day, a newly completed genome); content pull is information visitors want to extract from the site (e.g., information on a specific gene or disorder, lesson plans for a 10<sup>th</sup> grade biology class). In general the site does a good job of balancing these two elements.

It is important for curators to base major changes to page content and layout on user-based data rather than relying on their intuition, since the curator may not be representative of the intended audience for the page.

Comment	Source
I'm not sure this is what people are looking for, it seems so...	Internal interviewee remarking on the NHGRI FUNDING OPPORTUNITIES: TRAINING AND CAREER DEVELOPMENT page.
This is excellent. I can see the award mechanisms ...	An external interviewee remarking on the same page.

Comment	Source
I'm not sure anyone uses these shortcuts	An internal interviewee remarking on the shortcuts on the POLICY & ETHICS page.
Interviewee: I sometimes go to the page with the state legislation Interviewer: How do you get there? Interviewee: I use the link here [referring to the State Legislation link in the Shortcuts section]	Interview with an external interviewee

Maintaining a website requires traditional editorial skills but also a firm grounding in usability principles. For example, adding a new page to the site requires not only decisions about links and navigation to the page but also decisions about links and navigation on the page. Decisions about navigation to the page must take into account visitor expectations for locating the content. Finally, decisions about links and navigation on the page must consider the overall usability of the page. In other words, even though a content expert may produce the majority of the content on a page, the web-editing staff should help determine the best location and presentation for the content.

Recommendation:

Curation requires not only specific content expertise, but also expertise in web site content presentation and a view of the web site as a complete unit. In other words, a content expert must work closely with a web team member so the responsibility is a shared responsibility.

Specific recommendation:

- Train web-editing staff in usability/web content best practices.
- Ensure the web-editing staff has sufficient time and resources to:
  - Develop a current and complete understanding of site use based on frequent reviews of use data (e.g., webmaster emails, search box entries, web statistics).
  - Consider the site as a whole and develop new content for the site based on use data. For example, if the site needs more educational materials, the site editor should initiate development of these materials in collaboration with the appropriate people at the Institute or with partners beyond the Institute.
  - Use a proactive approach when reviewing pages with page owners. Ask for a complete check of all links and annotations on the page, particularly for off-site links.
  - Help page curators understand their audience.
  - Meet regularly with page curators.
- Encourage page curators to:
  - Develop a clear sense of ownership for their parts of the site.
  - Seek user-based data on their areas and pages so modifications can better support visitor interests.
  - Regularly engage with the web-editing staff.
- Most importantly, schedule regular (quarterly) in-person site review meetings between the web-editing staff and page curators.

General recommendation:

- Consider making both page ownership and the review schedule more public. At the moment determining page ownership is difficult. When an internal employee finds an out-of-date page she should be able to easily locate and contact the individual in charge of the page.
- Consider getting reviews and content recommendations from outside organizations for pages listing resources beyond the Institute, such as the GENOME HUB page or the SPECIFIC GENETIC DISORDERS page.

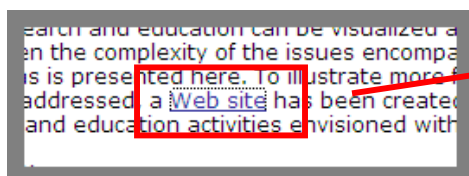
## 2.4 Minor issues

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This section covers issues that were either minor usability issues or examples of occasional inconsistencies.

### 2.4.1 Page title and link text do not always match.

Evidence: Examination of the site and interview data.



The link text is WEB SITE.

But the target page is ETHICAL, LEGAL, AND SOCIAL IMPLICATIONS (ELSI) RESEARCH

Recommendation:

- Use matching text for links and target page titles. In some cases an abbreviation may suffice so long as an immediate connection can be made between the link text and the target page.

Note: Using complete and descriptive link text is extremely important for screen readers (alternative browsers that read websites to vision-impaired visitors) where visitors may begin exploring a page by just listening to the links. (Sighted visitors often begin exploring a page in the same manner; they scan the page “looking for the blue”, i.e., reading just the links.) However, vision-impaired visitors using a screen reader do not have the benefit of interpreting the link’s target from the surrounding text, but rely on the actual link text to help them navigate.

## 2.4.2 Some pages do not anticipate likely visitor actions.

Evidence: Examination

Discussion: Some pages do not anticipate likely visitor actions. Those pages feel like dead-end pages to visitors.



On this page, this center section has no links. There is no obvious means of moving ahead if the program is of interest.

The FULL PROGRAM BROCHURE link on the SEE ALSO section should be in the center section since it gives directions for applying to the program.

Staff Search Results for: **miller**

Last Name	First Name	Phone	Email
Miller	Catherine	301-451-3645	cmiller1@mail.nih.gov

On this page, in order to search again the visitor must use the BACK button to return to the search box. Instead the results page could include the search box so the visitor can do another search without having to change pages.

Recommendation:

- Anticipate likely visitor actions on pages and provide a means for supporting those actions.
- Review the links in the SEE ALSO sections and ensure that critical links get moved to the center sections.

### 2.4.3 Numerical URLs annoy visitors, but do not hinder them.

Evidence: Examination, interview data, and survey data.

Discussion: The numerical URLs are mildly annoying for some visitors, but they are not a major stumbling block for the overall usability of the site. Visitors use the site structure to navigate, not the URL in the address box of the browser. Many visitors do not even notice URLs because URLs are typically not helpful on other sites.

When interviewees could not locate pages during the course of an interview it was not because of the numerical URLs; it was due to problems with the navigation. For example, navigation to the MINORITY PROGRAMS page is not intuitive enough, but the solution is not to give that page its own specialized URL, but instead to adjust the navigation by putting links to the MINORITY PROGRAMS page in places that match visitor expectations.

Numerical URLs have some benefits; they ease site maintenance and page portability. Because the URL is independent—it does not include the primary section (e.g., [www.genome.gov/grants/10002839](http://www.genome.gov/grants/10002839)) or the hierarchy (e.g., [www.genome.gov/research/online/researchresources/genomehub](http://www.genome.gov/research/online/researchresources/genomehub))—the page can easily be moved as the site is modified. In addition, the site hierarchy can easily be changed. On a smaller site with more static information, maintenance and page portability would be less of an issue, but genome.gov is both large and constantly changing.

However, numerical URLs are more difficult to remember than mnemonic URLs. This can be important when providing deep links in outreach materials. For example, a presentation to high school students that provides a deep link to the Talking Glossary has to list “<http://www.genome.gov/10002096>” as the URL. It is easy to think of a page name for the TALKING GLOSSARY, but it is not as straightforward when there are numerous pages with page titles that are both long and somewhat similar. For example:

- Ethical, Legal and Social Implications (ELSI) Research
- Ethical, Legal and Social Implications (ELSI) Research Program
- Ethical, Legal and Social Implications (ELSI) Program: Grant Abstracts A – M
- Ethical, Legal and Social Implications (ELSI) Program Publications and Products
- Sequences, Maps and Bacterial Artificial Chromosome (BAC) Libraries Funding Opportunities

Recommendation:

- Consider using mnemonic page names without including the hierarchy. For example: [www.genome.gov/greenlab.html](http://www.genome.gov/greenlab.html)
  - Determining mnemonic URLs would need to be a joint activity between the page curator and the web team since the site as a whole must be considered when assigning names.
  - Naming conventions must leave room for new pages with similar titles to be added.
- Do not use complete or partial hierarchical URLs because it is more difficult to move pages or modify the site structure when the hierarchy is embedded in the URL.
  - Partial hierarchy example:  
[www.genome.gov/health/clinicaltrialsFAQ](http://www.genome.gov/health/clinicaltrialsFAQ)

Problems: A page with this URL would be difficult to move out of the health section because the section is embedded in the URL.

- Complete hierarchy example:  
[www.genome.gov/careers/proftrainandcareerdev/predocDIRtrainaward](http://www.genome.gov/careers/proftrainandcareerdev/predocDIRtrainaward)



Problems: A page with this kind of URL would be difficult to move because not only is the section embedded in the URL but so is the full hierarchy. In addition, using this kind of URL would make changing the hierarchy of the site extremely difficult, since the URLs would be wedged to the existing hierarchy. Using this kind of URL and modifying the site structure could easily lead to URLs that reflect a structure that doesn't even exist, i.e., an imaginary hierarchy.

- Do not distribute numerous specialized URLs (e.g., [www.gard.gov](http://www.gard.gov), [www.gard.nhgri.gov](http://www.gard.nhgri.gov)) and separate websites because maintaining this over time will become unwieldy. In order to maintain a sense of unity, and to ensure visitors can continue to move about and locate information easily, the site should remain as a unit.

Note: Another government agency in this author's experience provided separate URLs and websites to each program within the agency. Now the agency finds that visitors are shunted from subsite to subsite, confronting different navigation schemes and conventions, as they try to locate information. The agency is now reversing its earlier practice and looking at ways to reduce the number of sites and URLs they support to make it easier for visitors to locate information.

- Consider using lightweight branding that does not conflict with the overall layout for pages that need to stand out as separate entities, such as the inclusion of the Encode logo on THE ENCODE PROJECT: ENCYCLOPEDIA OF DNA ELEMENTS page or the CURRENT TOPICS IN GENOME ANALYSIS 2003 page. The overall "brand" of the Institute is important to maintain because people rely on that to help them determine the credibility of the information they are looking at.

#### **2.4.4 Some pages do not stretch to accommodate large browser windows.**

Evidence: Examination and interview data.

Discussion: Although this is not a major usability issue, it unnecessarily restricts visitors with large monitors from benefiting from their extra screen real estate. And because the site is not uniform—Tier-2 pages are fixed-width while the Tier-3 pages stretch—the location of the right navigation changes dramatically when visitors on large monitors move between Tier-2 and Tier-3 pages.

Recommendation:

- Make all pages on the site stretch to fill the browser window.
- Ensure that the pages are still effective when sized to 800x600 pixels.

Note: It is extremely important to use a design that accommodates low-end systems. Many schools and homes still have equipment that can only size up to 800x600; and some visitors, particularly farsighted visitors, choose to keep their monitors at a low resolution. If design trade-offs are necessary, the trade-off should be in favor of supporting low-resolution monitors and systems rather than high-end high-resolution monitors, since the majority of visitors do not use the latter.

#### **2.4.5 Some content does not optimize for scanability.**

Evidence: Examination, survey responses, interview data.

Discussion: Some pages are destination pages, possible targets for visitors—pages where visitors are prepared to read through dense text. For example, a visitor is likely to read a news release, NHGRI report, or an FAQ but not the text in the center section of the Tier-2 pages. Other pages are navigation points where visitors are not ready to read. They are scanning, looking at headers, key words, and links as they make their next navigation



decision. When using a page as a navigation point, visitors avoid dense text and back away from pages that aren't easily scanned.

Some pages are both navigation points and destination pages. For example, when visitors first arrive on the page they may treat it as a navigation point until they determine that it is their target information. Or they may need to navigate within the page before they locate their target information.

Recommendation:

- When reviewing and producing content, consider whether the page is likely to be primarily a destination point or a navigation point, and organize the page accordingly.
- Optimize content for scanability.
- Consider using tables instead of annotated bulleted lists for dense pages. For example, the PROFESSIONAL TRAINING AND CAREER DEVELOPMENT page would be easier to scan if the information were in a table.

**Research Opportunities at NHGRI**

**Opportunities for students, scientists and educators to conduct research at NHGRI:**  
(See [Intramural Research](#) to learn about our investigators and their work)

- [Predoctoral Intramural Research Training Awards](#)  
Opportunities for college graduates, medical students and graduate students to gain research experience in NHGRI laboratories.
- [Summer Internship Program](#)  
Opportunities for high school, college and graduate students to conduct summer research in NHGRI laboratories.
- [Research and Training Opportunities at NIH](#)  
Additional training opportunities in the National Institutes of Health Intramural Research program.
- [Physician Scientist Development Program](#)  
Designed for board eligible/certified physicians who seek additional training to develop an independent research program that integrates the field of genomics with clinical investigation in genetic medicine.
- [The Genetics and Public Policy Fellowship](#)  
Genetics professionals with an advanced degree who are interested in national genetics health and research policy.

An annotated bulleted list can create text-heavy look and make it more difficult to scan.

**Research opportunities for students, scientists and educators at NHGRI:**  
(See [Intramural Research](#) to learn about our investigators and their work)

Opportunity	Eligibility	Program
Gain research experience in NHGRI laboratories.	College graduates, medical students graduate students	<a href="#">Predoctoral Intramural Research Training Awards</a>
Conduct summer research in NHGRI laboratories.	High school, college and graduate students	<a href="#">Summer Internship Program</a>
Receive training to develop an independent research program that integrates the field of genomics with clinical investigation in genetic medicine.	Board eligible/certified physicians	<a href="#">Physician Scientist Development Program</a>
Participate in policy analysis at the NHGRI and the ASHG	Genetics professionals with an advanced degree	<a href="#">The Genetics and Public Policy Fellowship</a>

Using a table for this content makes it easier to scan for opportunity, eligibility, and program name.

Also, putting the linked program name in the last column supports left to right scanning. When both the opportunity and the eligibility are a match, the visitor can keep moving to the right to click on the program link instead of having the backtrack to the left column.

#### 2.4.6 Some content is not suitable for the context.

Evidence: Examination, survey responses, interview data.

Discussion: On some pages the site does a good job of balancing these two elements, but in some cases the content doesn't match visitor expectations or needs.

Established by the National Human Genome Research Institute (NHGRI) and the Office of Rare Diseases (ORD), the Genetic and Rare Diseases Information Center employs experienced information specialists to answer questions from the general public, including patients and their families, health care professionals and biomedical researchers.

This is a block of dense text that begins with information that most visitors don't care about. Many visitors will not continue past the first few words to locate the more useful information at the end of the paragraph.

The Intramural Training Office (ITO) is located in the Office of the Scientific Director (OSD). Its mission is to serve as a focal point for training and career development, and to improve the overall training experience at the National Human Genome Research Institute (NHGRI).

The ITO offers a variety of information and resources related to mentoring, career development and funding opportunities. An important component of the ITO is to assist in the application process by identifying an NHGRI research lab with projects that match the interests of the candidate.

The mission statement at the top this page is not likely to be the primary information visitors are looking for. And some key information—that the office can assist with the application process and help match candidates to research labs—is buried in a paragraph.

Recommendation:

- When reviewing and producing content, consider whether or not the page is likely to be a destination page or a navigation point, and organize the page accordingly.
- Write content that matches visitor expectations and needs.  
When pages have a specific audience, work with representative visitors to understand their needs.

#### 2.4.7 Permission for using materials is difficult to locate.

Evidence: Webmaster queries.

Discussion: The webmaster queries show a pattern of repeated requests for permission to use material from the site.

Comment	Source
Hello First of all I would like to congratulate you because your website and your talking glossary. I'm interested in using some of that graphics for doing a little explanation prospect about DNA. I'd like to know if I can feel free to use it (including the author's name) or if you request doing something to me in order to use that graphics.	Webmaster query

Dear Webmaster, You have a wonderful Talking Glossary, and I especially like the illustrations - very clear and informative. I am currently writing my PhD thesis on computational prokaryotic promoter recognition and I need to include illustrations of the basic concepts from molecular biology I'm going to use in the text - what is DNA, RNA, nitrogenous bases, complimentary principle, etc. May I ask your permission to use some of the illustrations from your web site in my thesis?	Webmaster query
Hi! I have found a schematic drawing of DNA on a homepage: neanderthal-modern.com. It is published with your permission and now I wonder if I can use the same figure in a literature project I'm working with. I won't use it without your permission. Is there someone to ask?	Webmaster query

Recommendation:

- Include a link to a permission policy on pages with illustrations, especially those in the TALKING GLOSSARY.

#### 2.4.8 Some pages are not dated.

Evidence: Survey responses and Webmaster queries.

Comment	Source
I found this site excellent* except I couldn't locate the copyright date of the pages I visited (when each page was written/last updated)* and this info. is essential for citation.	Survey response
I would like to know how accurate this web site is. It indicates that it is last updated April 2002. Has there been any additional employment discrimination laws enacted since then?	Webmaster query
Good stuff on your website BUT....when was it published? revised? Is this material as current as possible? How would I know since there is no date noted anywhere? Please... do yourselves a big favor and learn to put the date of publication/revision on each item within your website. It would help those of us who are attempting to keep up with current and credible material, and it would make you look soooooo good.	Webmaster query

Recommendation:

- Include a “last updated” or “last reviewed” marker on each page.
- Include a copyright date where appropriate.

#### 2.4.9 Forms are not 508 compliant.

Evidence: Examination.

Discussion: The forms on the site are not completely 508 compliant. Although they work with a text-only browser such as Lynx, they do not have the necessary coding to make them easily navigable with screen readers (alternative browsers that read websites to vision impaired visitors).

Recommendation:

- Test the site for 508-compliance on a regular basis.
- Include listening to pages with a screen reader in the testing process.

### 3. Primary Sections

This portion of the report covers findings and recommendations specific to pages under each primary section. Each finding is described and accompanied by recommendations for addressing the issue.

Some sections are covered in more detail than others because the evaluation data not uniform. For example, several interviewees discussed the SPECIFIC GENETIC DISORDERS page in the HEALTH section at length. By contrast although many interviewees said that they pulled materials from the EDUCATIONAL RESOURCES section, when we visited the section during the interview they did not have specific observations to pass on.

#### 3.1 RESEARCH

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The RESEARCH section is unique among the Tier-2 sections because it must perform a difficult balancing act. It must preserve the differentiation between intramural and extramural for visitors who expect that terminology, while ensuring that visitors not familiar with that terminology can locate their target information. For visitors not familiar with the Institute, making a navigation decision based on which division to look under would be a major stumbling block. For example, a visitor might be looking information about technology transfer but not know that the Technology Transfer Office is part of DIR.

##### 3.1.1 Tier-2 Research page

Evidence: Examination and interview data.

Discussion: Interviewees, both internal and external, who were familiar with the Institute, were disconcerted by the lack of parallelism in the layout; DIR is obvious but DER is not. Only after careful perusal of the page did they determine that the left column was primarily DER content. However the interviewees also explicitly said that they believed that many visitors outside of the Institute did not understand the DIR/DER distinction and understood that the website must serve those visitors as well.

The challenge for this section is to:

- Provide a unified research front to serve visitors who do not know the DIR/DER distinction.
- Accommodate visitors who know the organization of the Institute.

Recommendation:

- Use the main RESEARCH page to expose visitors to the DIR/DER distinction, but concentrate on helping visitors make effective navigation decisions without needing to know ahead of time which division houses their target information.
- Provide HOME page shortcuts for EXTRAMURAL RESEARCH, INTRAMURAL RESEARCH, and RESEARCH RESOURCES. This should encourage visitors unfamiliar with the DIR/DER distinction to navigate to either the main RESEARCH page, which can provide more navigation assistance than there is room for on the HOME page, or the RESEARCH RESOURCES page.
- Present three areas on the main RESEARCH page: RESEARCH RESOURCES, DER, and DIR.
- In the RESEARCH RESOURCES area allow visitors to find research materials— tools, libraries, databases, clinical trials, etc.—without needing to know which division produced or houses the resources.

- In the DER and DIR areas, use labels (headings) that help outside visitors but also expose the intramural/extramural distinction.

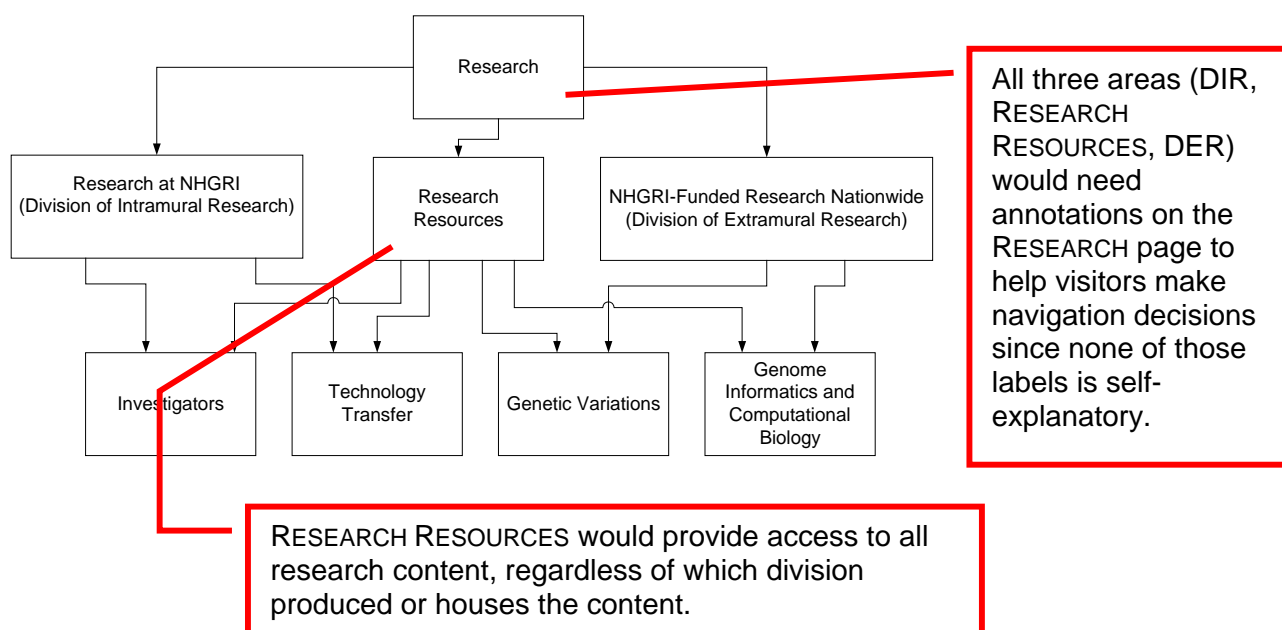
NHGRI-Funded Research Nationwide (Division of Extramural Research)

Research at NHGRI (Division of Intramural Research)

Link the division labels to a home page (Tier-2.5) for the division. These DIR/DER home pages should also concentrate on helping visitors navigate deeper.

- As is done now, provide shortcuts in each area. The shortcuts not only help visitors jump to pages of high interest but also provide a brief preview of the kind of content in each area.
- Pull important links from the SEE ALSO area into the appropriate areas.
- Get input from DIR and DER on the layout for the proposed DIR and DER home pages. Consider a page layout that puts navigation links at the top and explanatory overviews further down the page.
- The home pages for DIR and DER do not need to use identical layouts but should be visually related.

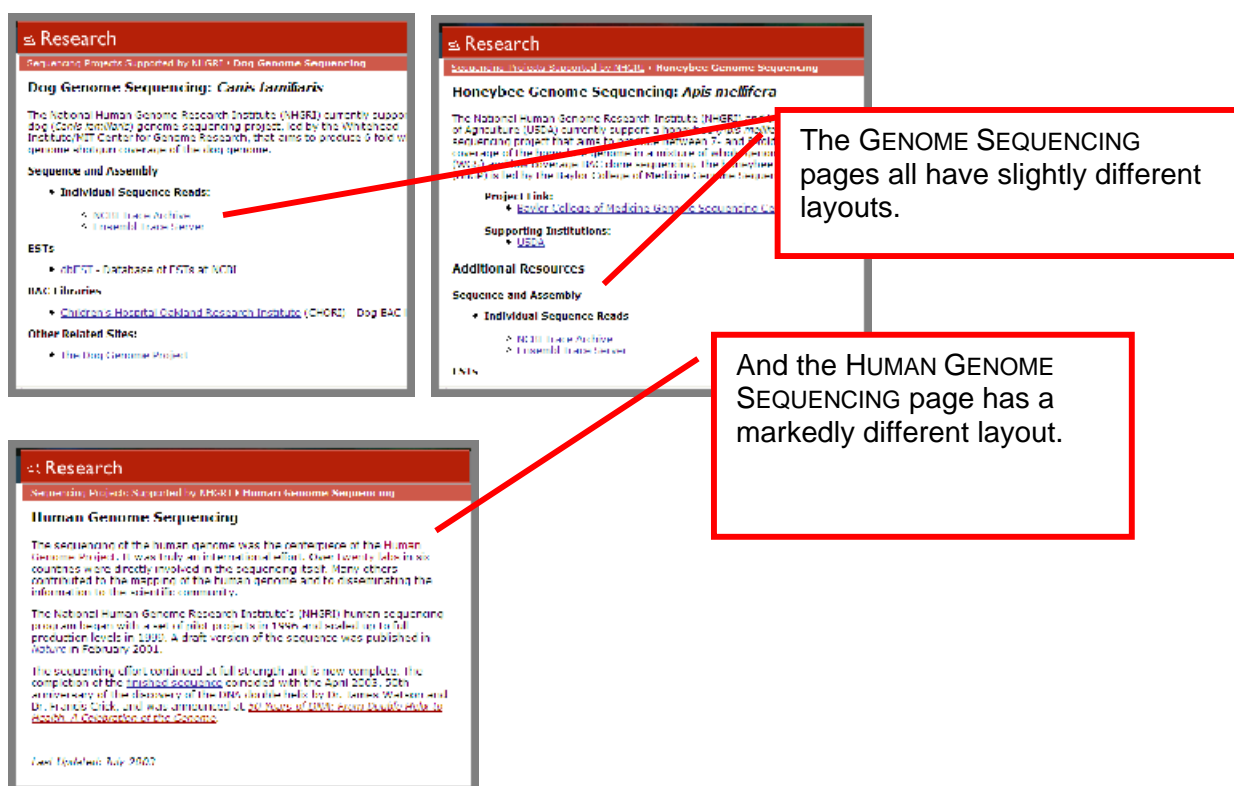
The sketch below shows the proposed arrangement



### 3.1.2 Inconsistencies on Research pages

Evidence: Interview data

Discussion: During interviews some research pages did not seem to be well-curated. One interviewee thought that the current RESEARCH RESOURCES page was missing many resources that should have been on the page. Another interviewee thought that several important resources from the resources page on the old site were missing on the page. It is also not clear why resources are split between GENOME HUB and ONLINE RESEARCH RESOURCES pages. In other research sections, there are pages that should be using identical layouts, but do not.



Recommendation:

- Review the pages in the RESEARCH section for consistency and completeness.

## 3.2 HEALTH

The HEALTH section serves not only patients and concerned family members but also genetic counselors and health professionals. Many interviewees said that they use these pages to locate web-based information to send to patients or to learn about genetic disorders. One news reporter said that he liked the GENETICS FAQ page because it contained consumer-level explanations, which he could use in his articles. However, there are several indicators from both the interview data and webmaster queries that indicate that some reorganization of this section would help visitors locate information more quickly.

### 3.2.1 Tier-2 HEALTH page

Evidence: Examination and interview data.

Discussion: The center column of the main HEALTH page does not help visitors navigate. Since it is one step below the HOME page, visitors are still scanning, looking to navigate deeper. They are not likely to read about GARD since visitors shy away from blocks of text when navigating.

Recommendation:

- Rework the page to help visitors navigate more deeply instead of highlighting a subsection (GARD).
- Consider a small area of news and announcements appropriate to health if there are sufficient highlights to keep the area dynamic. Repeat visitors will tune out a news area that does not change frequently.

- Instead of one dominant graphic, consider providing visual interest by using smaller graphics scattered about the page.
- Cluster the links for learning about genetic disorders together.
- Cluster the links for locating more general information together.
- Annotate all links.

### **3.2.2 GARD**

Evidence: Webmaster queries and interview data.

Discussion: Although GARD is prominently featured on the main HEALTH page, many visitors who would benefit from its services miss it. The reasons for this are:

- Many visitors bypass the main HEALTH page because they use the shortcut off of the HOME page to go directly to the SPECIFIC GENETIC DISORDERS page.
- Visitors who use the main HEALTH page are not likely to read about GARD, since it is a dense block of text and it begins with a series of facts that most visitors do not care about (when it was formed, where it is housed).
- The GARD page itself does not stand out as a definitive resource because it visually blends in with the other pages and is therefore easy to dismiss. And although the introductory paragraph is accurate, it does not "sell" the center and is not easily scanned. Visitors still navigating, and therefore not reading paragraphs, may scan the contact information without any context.
- On the SPECIFIC GENETIC DISORDERS page, the only link to GARD is in the SEE ALSO section, which not all visitors notice. Additionally, the link is not annotated in the SEE ALSO section, making it less likely that visitors will recognize as an important link.

Recommendation:

- Brand the GARD page using visual markers.
  - Put links to GARD in the center section of the SPECIFIC GENETIC DISORDERS page
  - Rewrite the top part of the GARD page to make it scannable and emphasize the information visitors care about:
    - Information provided on 6000+ genetic disorders
    - A trained genetic counselor will provide the information
    - Anyone can request information
    - Responses in 5 to 10 days by phone or email
- Put the details of where and when it was established at the bottom of the page.

### **3.2.3 SPECIFIC GENETIC DISORDERS page**

Evidence: Webmaster queries and interview data.

Discussion: This page is likely to be a source of frustration for visitors seeking information about a disorder not listed on the page. Issues with the page are:

- The introductory paragraph is not the kind of information most visitors to this page are seeking. Visitors coming to this page are focused on finding information on a specific disorder and this paragraph, although informative, does not help them in that goal.
- No rhyme or reason for the list. "Why were these conditions chosen to be highlighted?" was the most frequent remark during interviews that covered this page. Since the list is so short, there is an implication that these disorders are the ones under investigation at NHGRI, but that is not the case. One internal investigator looking over the list

commented, “this is a weird list” – meaning that he could not see any connecting element between them.

- The page is inconsistent. For example:
  - Additional resources are listed for only two disorders.
  - Explanations are provided for only two disorders.
- It is hard to learn which disorders are under investigation at NHGRI.
- Most importantly, for visitors seeking a disorder not listed on this page, the page feels like a dead-end.
  - Visitors might find the disorder they are looking for on the ONLINE HEALTH RESOURCES, but that page is overwhelming and difficult to navigate since it is so long.
  - GENETIC AND RARE DISEASES INFORMATION CENTER (GARD) is listed on the right, but many visitors tune out the right navigation or do not associate GARD with where they need to go.

Recommendation:

- Provide a single complete list all the disorders that genome.gov provides information on. Do not annotate the list (in order to keep it scannable). Mark disorders under investigation at NHGRI.
- For each disorder listed, provide a page modeled after the existing disorder pages (e.g., LEARNING ABOUT BREAST CANCER, LEARNING ABOUT CHARCOT-MARIE-TOOTH DISEASE). Consolidate the information for each disorder onto one page. In other words, the content on the ONLINE HEALTH RESOURCES page for a particular disorder should be merged onto the LEARNING ABOUT pages.
- Provide an explanation of why the listed disorders were selected to have detailed information available.
- Provide highly visible links giving visitors options on where to go when their disorder is not listed such as:
  - The Genetic Alliance search page.
  - GARD
  - OMIM (annotate that this information is scientifically oriented)
- Add a link to GENETIC TESTING FAQs to the SEE ALSO section

### 3.2.4 ONLINE HEALTH RESOURCES

Evidence: Examination and interview data.

Discussion: There is a wealth of information on this page, but the size of the page makes it difficult to navigate. The page really has two distinct sections, general health resources and specific disorder resources.

Recommendation:

- Provide a prominent link to GARD at the top, with GARD branding.
- Move the specific disorders content to individual LEARNING ABOUT pages.

## 3.3 POLICY & ETHICS

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This section is of considerable interest to the general public. 28% of survey respondents reported “Ethics” as an area of interest. Several interviewees said that they use content from



this section both for personal reference and as a basis for educational and outreach materials. Many interviewees using the HEALTH section said that they also use content from this section.

In this center column, the news-like layout (headline, dominant graphic, dated article) is more effective than it is on other Tier-2 pages, since it actually is a news brief.

### **3.3.1 High interest links require scrolling**

Evidence: Interview data

Discussion: Several interviewees indicated that items in the shortcuts section on the left were of high interest (ENACTED STATE LEGISLATION: HEALTH INSURANCE DISCRIMINATION, ENACTED STATE LEGISLATION: EMPLOYMENT DISCRIMINATION), and locating those requires scrolling on most monitors.

Recommendation:

- Consider reducing the news brief at the top of the center section and providing a link to the complete article in order to free up space.
- Rearrange the links to move more frequently visited links to the top.

## **3.4 EDUCATIONAL RESOURCES**

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This section serves a wider audience than teachers and students. Both internal and external interviewees said that they extract consumer-level language and materials from this section. The extracted content goes into outreach materials such as presentations and talks, as well as professional teaching materials.

One teacher was hoping to find teaching materials about DNA forensics. He said that it was a hot topic since several popular TV programs refer to it. In his experience it is easier to get his students into science when he can hook into something that has already caught their interest.

Note: the TALKING GLOSSARY is one of the most frequently visited pages on the site!

Overall recommendation:

- If the Institute chooses to develop additional teaching materials, involve teachers in the process to ensure that the materials meet their needs.

### **3.4.1 Ordering information**

Evidence: Interviews and webmaster queries.

Discussion: An interviewee who works with teachers said that websites for teachers frequently have an “order here” button and so teachers tend to look for that. But there is no equivalent on genome.gov. Several webmaster queries substantiate that comment.

Comment	Source
Gentlemen: I teach biology at Bernalillo High School. Please send me 60 copies of the booklett, "Genetics, the future of Medicine". My address follows: [address provided]	Webmaster query

Hi, I hope you can help me. I subscribe to 'Nature - International Weekly Journal of Science' and sometime ago a CD ROM came with the magazine. The CD ROM was titled 'The Human Genome Project' and is excellent. I am Head of Biology in a school in Suffolk, England and used the CD ROM as a teaching resource. Unfortunately, the CD ROM is broken. A pupil in one of my classes stood on it. I would like another copy. Do you have any copies available? If not, do you know where I could find another copy? Best wishes, [name]	Webmaster query
I am wondering if there are any materials, like posters or brochures, that are specific to DNA Day on April 25, 2003? I am new this year in the position of Genetics Program Director at the Indiana State Department of Health and it seems to me that DNA Day would be a great means of public education and awareness of genetics! Any help or suggestions you can provide to "advertise" DNA day is greatly appreciated. Thank you!	Webmaster query

Recommendation:

- Include a page that consolidates materials (CDs, posters, brochures, video tapes) available for downloading or ordering and supports the download and ordering process.
- Provide alternate means of obtaining downloadable materials that are too big to download successfully over a slow connection.
- Include a list of materials no longer available with recommendations for alternatives.

## 3.5 CAREERS & TRAINING

This section attracts both visitors seeking opportunities for themselves and visitors seeking opportunities to pass on. For example, research coordinators will check this section of the site to see if there are opportunities of interest to their constituents.

### 3.5.1 Tier-2 CAREERS & TRAINING labels are not effective

Evidence: Examination and interview data.

Discussion: Interviewees reacted well to the CAREERS & TRAINING label; the content in the section matched their expectations. But once on that page they did not find the label PROFESSIONAL TRAINING AND CAREER DEVELOPMENT useful because it was too generic and formal. When they moved deeper, they were navigating based on the annotation, not the label. In addition, the label PROFESSIONAL TRAINING AND CAREER DEVELOPMENT was not effective in the SEE ALSO section on other pages. Also, INTRAMURAL TRAINING OFFICE is not an informative label for visitors who do not know what the word “intramural” means.

Recommendation:

- Rework the hierarchy, labels, and headers used in the CAREERS & TRAINING section (see next section)
- If possible, test the labels with representative users to see if they are effective.

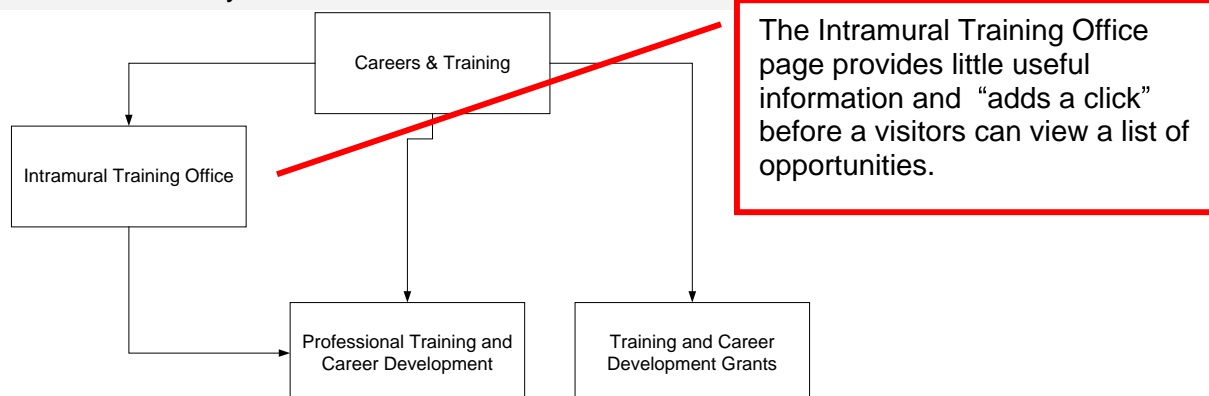
### 3.5.2 Incomplete and overly complex hierarchy

Evidence: Examination

Discussion: The natural hierarchy in this section is relatively shallow, but the section imposes a complexity that is not necessary. There is also a lack of parallelism on the PROFESSIONAL TRAINING AND CAREER DEVELOPMENT page. The INTRAMURAL TRAINING OFFICE page does not list opportunities, but the TRAINING AND DEVELOPMENT GRANTS page

does. Several interviewees were looking for specific training opportunities and could not locate them (MINORITY PROGRAMS, JOHNS HOPKINS UNIVERSITY GENETIC COUNSELING GRADUATE PROGRAM).

#### Current Hierarchy



#### Recommendation:

- Use an alternative layout that does not require a highlighted subsection for the Tier-2 page.
- Consider providing visual interest with smaller scattered graphics rather than one dominant graphic.
- Provide these annotated links from the main CAREERS & TRAINING page:
  - RESEARCH AND EDUCATION OPPORTUNITIES AT NHGRI (currently PROFESSIONAL TRAINING AND CAREER DEVELOPMENT)
  - TRAINING AND CAREER DEVELOPMENT OPPORTUNITIES FUNDED BY NHGRI
  - MINORITY OPPORTUNITIES (BOTH AT NHGRI AND FUNDED BY NHGRI)
  - JOBS AT NHGRI
  - HUMAN RESOURCES AT NHGRI

## 3.6 GRANTS

This section seems to work well for visitors interested in this content. The two pages which interviewees gave as primary targets—the FUNDING OPPORTUNITIES page and the FUNDED GRANTS AND GRANT HISTORY page—are easy to locate. However there were curatorship issues with some of the pages listing programs and requests for applications.

### 3.6.1 Current status on RFAs and PAs

Evidence: Examination and interview data.

Discussion: There are two issues with the current listings of RFAs and PAs.

- A visitor must click into each and every item to learn the receipt dates.
- Some expired items are still listed. In one case an internal interviewee said that was because it was still accepting proposals but this was not noted on the page.

These are pages where a last-updated marker would be especially helpful, since it would tell visitors the last time the list was reviewed (and expired items removed). One interviewee

said that she always calls or emails about programs on federal web sites with a start date before 2000 because they are often expired even though they are still posted.

Recommendation:

- Curate this content carefully.
- List the status and be explicit (e.g., receipt date, expired but still accepting proposals).
- Move expired items no longer accepting proposals to the funding history pages.

## **3.7 Newsroom**

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Both interview and survey data show that news is of high interest to many visitors. One interviewee said that she would sometimes locate a news release on a topic because the news release is like a “mini” home page, providing an explanation and description of the topic along with links to supporting information.

### **3.7.1 Labeling issue**

Evidence: The label CURRENT RELEASES confused one interviewee who saw that the oldest one listed was dated June 2003 in the list and was trying to locate releases from Jan – May 2003.

Recommendation:

- Rename CURRENT RELEASES to 2003 RELEASES.

## **3.8 ABOUT NHGRI**

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Most, but not all, of the content in the ABOUT NHGRI section is a good fit for the section. Some content is located under the organizational entity (division, office, branch) that administers the content rather than where visitors would expect to find it.

### **3.8.1 Minority programs**

Evidence: Examination and interview data.

Discussion: The location of this content reflects the Institute’s internal organization but does not match visitor expectations. Visitors do not associate it with ABOUT NHGRI. One interviewee involved in outreach said that he always gave out the direct URL to the MINORITY PROGRAMS page at exhibits and talks because otherwise people could never find it. Another interviewee looked for this page during the interview and was unable to locate it until she was directed to pay attention to the SEE ALSO section.

Recommendation:

- Provide prominent links to this content in the RESEARCH, HEALTH, POLICY & ETHICS, EDUCATIONAL RESOURCES, GRANTS, and CAREERS & TRAINING sections.

### **3.8.2 INTRAMURAL TRAINING OFFICE**

Evidence: Interview data.

Discussion: The location of this content reflects the Institute’s internal organization but does not match visitors’ expectations. A link to this page is prominent on one of the top-level CAREERS & TRAINING pages, so visitors do find the page, but it is unexpected to move from CAREERS & TRAINING, to ABOUT NHGRI, and then back to CAREERS & TRAINING again.

Recommendation:

- Relocate this content to CAREERS & TRAINING.

### 3.8.3 April 2003 materials

Evidence: Interview data.

Discussion: Interviewees involved in outreach and education said that they are still using the April 2003 National DNA Day materials but that its location, under ABOUT NHGRI, was not intuitive.

Recommendation:

- Relocate this content to EDUCATIONAL RESOURCES.

### 3.8.4 Organization chart

Evidence: Examination and interview data.

Discussion: People process information differently. For some people, a visual is extremely helpful. Although a tree structure is provided in PDF form, it is not interactive and therefore not as useful as it could be if it were a clickable chart that allowed visitors to explore it in a more visual manner. Two interviewees also said that the chart is out of date. Visitors trying to use the current organization pages were frustrated since it required considerable clicking to locate an individual if you weren't sure which section the person was in.

Recommendation:

- Supplement the text version of the organization chart with a clickable version.

### 3.8.5 Staff Search results

Evidence: Examination, interview data, survey results.

Discussion: Learning the title or office number of a NHGRI employee who is not a DIR investigator is difficult. The STAFF SEARCH only provides a phone number and the phone number is not always accurate. Also, the STAFF SEARCH does not support doing a second lookup after an initial lookup since the search box is not provided along with the results.

Comment	Source
There should be a directory page enabling one to view the staff name* e-mail* tel* bldg. number* title* etc...	Survey results

Recommendation:

- Provide more complete information.
- Provide a search box along with the results to facilitate another search

## 3.9 HOME

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Many internal interviewees said that they rely on the HOME page for their NHGRI news; when they open the HOME page they do a quick scan of the news sections (bottom left and right) as well as the CALENDAR before moving on. Even if they do not read the releases, just scanning the news headlines and calendar listings makes them feel more in touch with what is happening at the Institute.

### 3.9.1 Cluttered looking HOME page

Evidence: Interview data and examination.

Discussion: Some interviewees mentioned that they found the HOME page too busy and that made it hard for them to process the information on it. On the HOME page there is no place

for the eye to rest. Given the busy navigation at the top and on the right, this should be the center section, but that section is visually cluttered.

Recommendation:

- Reduce the visual clutter on the HOME page. The current skeleton (banner, navigation, right side) is busy and that should be balanced by a simplified center section.

### **3.9.2 Human Genome Project link**

Evidence: Interview data and survey responses.

Discussion: Survey respondents checked the HUMAN GENOME PROJECT as an item of high interest. It was second after LATEST NEWS ON GENOMICS AND GENETICS. NHGRI has well-written content about the Human Genome Project aimed at the general public, but the HOME page link goes to NCBI instead. Many of those respondents were students or non-scientists; the NCBI page is not the most appropriate link for them.

Recommendation:

- Link to the ABOUT THE HUMAN GENOME PROJECT page instead of the NCBI page. Or include both links.

### **3.9.3 House image map**

Evidence: Examination and interview data.

Discussion: Some words on the house image are clickable, but not all even though there are pages within the Institute that would be appropriate targets for those words.

Recommendation:

- Link all the words on the image map.

## 4. Next Steps

This report includes a wide variety of recommendations. However, before proceeding with changes to individual pages, the web team should step back and consider the site as a whole for several reasons:

- Although the general navigation scheme is working, both the SEE ALSO section and the Tier-2 pages need attention. Those problems could be addressed individually but it may be that an alternate skeleton (banner and primary navigation) would offer a solution that addressed the issues on a more global level.
- Some solutions require a design decision before changes can be made. For example, before in-page jumps can be consistently differentiated a decision must be made about how the jumps will be marked.
- The high-level navigation (banner and primary navigation) and low-level navigation must work together. An alternate skeleton might suggest a different means of differentiating in-page jumps than the current skeleton.

Also, the report does not attempt to exhaustively list all instances of problems. A careful examination of the site is required to identify all pages that need attention.

Recommendation:

- Consider alternate skeletons (banner, search, and primary navigation) for the HOME page, Tier-2 pages, and Tier-3 pages. Explore both minor tweaks to the existing skeleton and more radical changes. The focus should be on addressing the usability issues identified in this report while not breaking the parts of the site that work well. The web team is in a stronger position than it was when the site was first designed because it now knows the range of content that must be accommodated. Begin this process by sketching wireframes (without visual treatment) using simple sketching tools. Sketch representative pages for different kinds of content (e.g., a page with in-page jumps, a page with a table). Please note that after considering alternatives it may be that the current skeleton, with modifications to address the SEE ALSO and Tier-2 problems, is the best approach.
  - *I suggest starting with wireframes because often design efforts focus on visual treatment (colors, graphics, etc.) too early. The process should determine placement and labeling before it proceeds to visual treatment. For wireframing, I suggest Visio or PowerPoint because wireframing in HTML or Photoshop often leads to focusing on the wrong level of detail.*
- Determine layouts for the content areas of each Tier-2 and Tier-2.5 (DIR, DER) pages to address the issues listed in this report. These do not need to use the identical layouts but should have a common visual differentiation from the Tier-3 pages.
- Once design decisions, both large and small, have been made, examine the site carefully to locate pages and sections that need to be updated.
- Get to know your audience.
  - Talk to representative visitors to understand their needs in order to produce content that matches visitor expectations and needs. For example, talk with students who are in the process of looking for a summer internship to learn what information they look for when investigating options (what information is helpful, what information is critical, what draws their attention, etc.) and how they use the information.
  - Involve both page curators and the web-editing staff in this effort.

## 5. Appendix A: Usage Patterns and Methodology

### 5.1 Usage Patterns

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#### 5.1.1 Power users

Power users of genome.gov have two characteristics. They understand how NHGRI is organized and they use genome.gov regularly. They are not necessarily sophisticated web users, but they use genome.gov frequently enough that they are comfortable with the site. They have a good sense of what they can expect to find on the site and where to find it. Some of these users make effective use of SEARCH because they know enough to determine which results are likely choices. Some of them even use SEARCH as a shortcut. For example, “genome hub” entered in the search box will provide a one-step link to the GENOME HUB page since it is the top result. One power user utilized the NEWSROOM as an alternate navigation strategy; she knew that if she could find a news release on a particular subject that the news release would have links to related pages. For her, a news release acts as a mini home page for the subject matter.

Many power users rely on genome.gov as the primary source for their outreach and educational materials. They repurpose the content for reports, presentations, magazine articles, public talks, and course materials for all levels (health professionals, the general public, and K-12). Several interviewees noted that the content in the EDUCATIONAL RESOURCES section is particularly useful for outreach materials because it provides consumer-level materials.

#### 5.1.2 Internal NHGRI users

During interviews with internal NHGRI visitors, a few key points emerged regarding the site:

- The site is an integral part of the workflow for some NHGRI employees. In some cases they are preparing outreach materials, in other cases they are using research content on the site.
- Many NHGRI employees receive queries, both through email and by phone call, from the general public, but most not to an overwhelming level. Often these queries have nothing to do with the employee's area of expertise—the person contacting them may not know much beyond the fact that they work at NHGRI. Everyone interviewed at the Institute is clearly committed to answering these queries from the general public, but do not always know the best information to provide when the request is outside their area of expertise. For example, not all the internal interviewees are familiar with the content of the HEALTH section, which is specifically written for the general public.

Recommendation:

- Help internal employees respond appropriately. Provide them with recommended responses for typical queries.
- The Director's office (Dr. Collin's office) handles some of these calls. Ask the staff to track these calls in the same way that webmaster queries are tracked. Include this data when curating the content.

Note: Some people will continue to call and email the Institute rather than look for their answer on the site. But ensuring that as many answers as possible are available on the site can help reduce the number of phone and email queries and make it easier to respond by sending URLs to pertinent pages.



### 5.1.3 Visitor profiles

Very few visitors use the entire site. Two or three sections were the primary focus for most interviewees with occasional forays into other sections. The list below gives sample profiles of visitors and their activities; but it is not an exhaustive list.

- Research coordinators at universities and organizations keeping tabs on on-going research at NHGRI as well as tracking funding opportunities to forward to researchers they are working with.
- “I like science” visitors looking to expand their personal knowledge.
- Staff at advocate and education organizations creating outreach materials.
- College students looking for information and tools for their classes, papers, and research, as well as for training, internship and postdoc opportunities.
- Patients, concerned family members, genetic counselors seeking information on a specific genetic disorder or genetic testing.
- Teachers looking for teaching materials.
- Interested citizen, patient, or health professional looking up state and federal legislation.
- News and magazine reporters looking for story ideas and story backgrounds (e.g., funding awards, funding history, the history of the human genome project).
- External researchers looking for tools, databases, and funding opportunities.
- High school students looking for homework help.
- ELSI researchers, both internal and external, using content from the research pages.
- Internal NHGRI employees extracting information to be used in reports and presentations.

### 5.1.4 Personal Preferences

Some visitors find the site too busy. A few interviewees said that it was hard to find information because there was too much “stuff” on the pages. A few survey comments also noted that the site is confusing and text heavy. However during interviews those who said the site was too busy were still able to navigate and locate content. So even though they did not like the layout, and it felt like hard work to process all the options on a page, they were able to use it. In contrast many interviewees and survey respondents said that they found the site easy to navigate and the content excellent. The HOME page shortcuts that were visual clutter to some visitors were important to other visitors.

Recommendation:

- Choose simpler layouts over busy layouts where possible. For example, since the Home page is visually busier across the top and along the right than other pages, balance that with a simple center section.
- Use more tables to enhance the scanability of the pages and reduce visual clutter.

## 5.2 Methodology

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Data for the evaluation was collected from several sources:

- Examination of the site by a usability expert for compliance with best practice guidelines (listed in a later section).
- A survey posted on the website during the month of December 2003 and the first 2 weeks of January 2004.
- Interviews with internal stakeholders and visitors from DIR, DER, and OD.

- Interviews with external visitors identified by two means:
  - Contacts provided by internal stakeholders
  - Optional inclusion of an email address in a survey response.
- Webmaster queries from March 1, 2003 to July 31, 2003.
- Search box entries from Jan 1, 2003 to October 31, 2003.
- Web statistics from September 2003

The data is most useful when viewed as a whole rather than as individual pieces. No single source of data provides a complete picture of the site, but taken together information and patterns emerge. For example, students in high school and college are clearly using the site. The table below lists data from three different sources relating to student use of the site.

Source	Data
Survey response	there is not enough information for me to write three pages on
Webmaster query	There are already many possibilities in the field of genetics, such as curing hereditary diseases and increasing our life span, and we've only just begun our research on the human genome. However, this has also brought up a great deal of controversy, such as cloning and genetically engineering our babies. What possibilities do you see in the next fifty years and what possible conflicts do you think could occur?
Interview with a masters student	She hadn't used the site much, but she said that it would be extremely useful for doing background research for her classes. During the interview she was excited to discover the SPECIFIC GENETIC DISORDERS, ONLINE HEALTH RESOURCES, and ENACTED STATE LEGISLATION pages since they covered topics that had come up in her classes that she needed to know more about.

The following sections give a brief overview of each of the data sources and highlights important points for each. Appendix C (Raw Data) contains a listing of source documents for the data.

### 5.2.1 Summary of Survey Results

The survey contained questions about visitor's experience on the site and the visitor's demographics. Responses to individual questions were always optional and some respondents choose to complete only a subset of questions. The number of respondents is not statistically significant however the trends in the responses are relevant when combined with the other evaluation data. Highlights from the responses are listed below.

#### About the site:

- **Question 1 (Frequency of use):** More than 50% of the respondents indicated that this was their first visit to the site. Although during interviews many external interviewees said that they visit the site frequently, it appears that more frequent visitors did not choose to complete a survey as often as first time visitors.
- **Question 2 (Target information):** LATEST NEWS and the HUMAN GENOME PROJECT were the most frequently checked items for this question with GENERAL SCIENTIFIC INFORMATION and ETHICAL ISSUES as the next most popular items.

- **Questions 3,4,5,6,7 (Success, failure, and reasons):** These responses are more informative when taken as a group rather than individually. For instance, most of the respondents said that they were successful in locating their target information. But some respondents who checked off NOT SURE indicated in the free-form responses that they were just browsing or that their lack of success was not due to the site's navigational structure but rather that the site did not contain their desired information. Others mentioned specific information that they could not locate. That list, along with the web-master queries should be reviewed. In some cases the information the visitors was seeking may not be appropriate for the site. For example, one respondent was looking for "Something relating to the idea that we all come from one of 33 original females and that our genes contain a record of our dispersal across the globe." In other cases however the navigation leading to the target information should be reviewed and possibly adjusted.

#### **About the visitor:**

- **Question 8 (Role):** Less than half of the respondents completed this question so it was not useful for locating patterns of activity and interest.
- **Question 9 (Age range):** One pattern from this data shows that respondents over 25 were less likely to provide their email for an interview. Of the respondents who provided their email address a large percentage of those were under 25.
- **Question 10 (Education Level):** Many respondents choose not to provide their education level. Of those who responded the highest numbers were for CURRENT MIDDLE OR HIGH SCHOOL STUDENT or GRADUATE/PROFESSIONAL DEGREE.
- **Questions 11,12,13,14 (web and computer experience):** These responses show a high level of computer and web usage. Over 80% of responses indicated daily computer usage and over 70% indicated daily WWW usage.
- **Question 15 (other web sites visitors use):** Some visitors clearly keep up with the news; they listed multiple news sources. And of course, www.google.com had multiple listings.

#### **5.2.2 Internal interviews**

Internal interviews included members of DIR, DER, and OD. Interviewees were asked about their own use of the site and for their thoughts on the effectiveness of the site for external visitors. Most of the internal interviews were conducted in-person, which allowed for additional information gathering since the evaluator could observe the interviewee using the site.

Work use: Many interviewees said that the site is part of their workflow and that they access and use content on the site regularly. Some are using research pages, particularly for ELSI research, while others are extracting content to be repurposed into reports, presentations, and outreach materials. In other cases internal use of the site was limited to tracking down pages to send to outside constituents.

Views on outside usage: Some internal interviewees had a hazy picture of who would be using the site because they are not working with or collaborating with people outside the Institute on a regular basis. Or they had a definite view on their constituents (e.g., potential grantees or potential post-docs) but little sense of overall site audience and usage as a whole.

#### **5.2.3 External interviews**

The external interviews were conducted over the phone due to travel considerations. Most were with professionals using genome.gov as part of their job. One item of note is that many of the external interviewees who visit other sites regularly were particularly complimentary about genome.gov; they find the site easy to use and the content useful compared to other sites.

## 5.2.4 Webmaster queries

The webmaster queries are a good source of use data (after the nonsense ones are weeded out). An oft-repeated request can point to a hole in the content or navigation. In order to usefully process the queries they must be culled and categorized on a regular basis. For example, there are several requests for permission to use or reference content on the site over the course of four months. Taken by themselves they do not stand out since they are scattered across those four months but when categorized and grouped together they are noticeable.

The queries can make for interesting reading; they run the gamut from requesting help with a technical matter on the site to asking about very specific genes.

### Sample webmaster queries (7 out of 276)

Many years ago, when the Human Genome Project began, I saw a PBS special called "Children of Eve," or something to that effect. The program presumed that the Human Genome Project would answer this question: Are we all related? Has the project answered that question? If so, where do I find the information? If not, do you believe the project will answer the question? Is anyone working on such a notion? I find this concept to be the most compelling social notion of all time, so I would sincerely appreciate a response. I could not find such information on your website. Thanks, and Have Fun!

I'm having a difficult time trying to find information on Greig cephalopolysyndactyly syndrome. I have looked through your website and through specific areas relating to it, and have come up blank. Do you have any material that I could read about this syndrome? Or can you give me the title to a book involving this genetic disease? Thank you for your time.

My name is [name] and I am a BSW Intern for CuraScript Pharmacy in Orlando, Florida. We are currently updating our company website, <http://curascript.com>, and are in the process of developing an On-line Resource Guide for our patients' use to be included under Patient Services. Due to the valuable and pertinent nature of the data available through your website, we would like to include information and a link for the National Human Genome Research Institute as part of our resources. I would like to request permission to attach such a link and I would require written consent for confirmation in the form of E-mail, letter, or fax. Can you provide me with the permission to link or, if not, provide me with the appropriate contact to attain such authorization?

Hi ! Recently I saw the video "Deciphering Nature's Alphabet". I was told that it was produced by NHGRI. Can you, please, advise me where I can buy this video ? Thank you very much.

I am looking at your website wherein you give information on rare disorders

I know a gentleman who is currently in San Quentin State Prison. He has a degree already and wants to get a degree in Associates Arts Criminal Justice. Can you please mail him some information on correspondence courses that he can take.

Is the NHGRI website and its contents public domain? I work for a non-profit organization that mirrors sites for developing countries on their intranet sites. Specific parts of the NHGRI site would be helpful to those university students learning medicine. Thanks!

can birthdefects change bone structure and make one look different in the face

My daughter has this genetic abnormality and I was wondering if you might have any information on it?!? 46,xx,add (9) (q34.1) .ish der (9) t (9;13)(q34.1;q32) (wcp13+,9qtel-,13qtel+)

### 5.2.5 Search box entries

Search box users tend to follow one of two patterns, either the search-first or search-last pattern. As one might surmise, search-first users go straight for the search box hoping to hit the jackpot. These users revert to using the navigation when the search fails to produce useful results or after the search results have helped them get close to their target. Search-last users browse the site first, using the navigation to look for their target and use the search box as a last resort when browsing the site fails. In either situation, the search box entries are a good source of use data; they show what kinds of information some visitors were looking for. Like the webmaster queries, the data must be reviewed and categorized on a regular basis before it is useful. The search words between Jan 1 to Oct 31, 2003 included over 6000 unique entries. The table below shows the 40 most common search box entries (split into two groups of 20).

20 most common entries		Next 20 most common entries	
# of occurrences	Search box entry	# of occurrences	Search box entry
100	testing and treatments	22	stem cells
88	homeodomain	22	gene
86	microarray	21	chromosome
70	glossary	21	ELSI
86	human genome project	20	pictures
60	cloning	20	BIC
58	progeria	20	10000884
45	gene therapy	19	genetic engineering
44	DNA	18	stem cell
37	dog	18	race
37	cystic fibrosis	18	homeodomain protein
37	aids	18	collins
34	polydactyly	17	nih director
31	sickle cell anemia	17	breast cancer
28	human genome	16	homiodomainprotein
28	genetic counseling	16	chromosomes
27	genome	16	brca1
24	dna	16	SNP
24	cancer	15	obesity
24	Parkinson's	15	history

### 5.2.6 Web statistics

The web statistic used for this evaluation was the list of most frequently visited pages. Note that both the TALKING GLOSSARY and the SPANISH GLOSSARY are popular pages. The table below shows the ten most frequently visited pages in September 2003.

# of Hits	Page
52576	HOME
21451	EDUCATION KIT
19874	GLOSSARY
9499	SITE SEARCH
9584	GENOMIC RESEARCH
7535	SPANISH GLOSSARY
5590	STAFF SEARCH
5383	EDUCATION (TIER 2)
5323	COURSE 2003
3404	ELSI Research

## 5.3 Final thoughts on data gathering

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This evaluation pulled together data from several sources. Some of the sources are not on-going ventures, such as the survey and the interviews, but other sources will continue to provide usage data that the web team can and should use.

Recommendation:

- Actively gather usage data and examine it on a monthly basis. This includes:
  - List of the most frequently visited pages.
  - Search box entries.
  - Webmaster queries, both from email and by phone.
  - Other requests for information handled by the Institute such as inquiries to Dr. Collin's office.
- Categorize the data and analyze it for trends.
- Consider the data when curating content.

## 6. Appendix B: Best practice guidelines

These guidelines, derived from a number of authoritative sources, reflect accepted practice in the usability field. The examination of the site by a usability analyst compared the site against these guidelines.

- Match User Tasks and Mental Model
  - Support work flow
  - Represent tasks from users' point of view
  - Use a hierarchy and organization that represents the users' point of view
- Speak the User's Language
  - Avoid jargon
  - Avoid specialized in-house terminology for public sites
- Provide Consistency
  - Provide controls that are consistent in wording, placement and meaning
  - Use only one word or term used to describe any item
  - Match links and buttons to the titles of the target pages
- Meet Standards
  - Maintain appropriate system and platform standards
  - Maintain appropriate corporate standards
  - Meet Accessibility (section 508) requirements
- Maintain Visibility
  - Provide clear persistent indication of the current location and system status
  - Label all functionality clearly
  - Support recognition rather than recall
  - Keep actions, objects and options visible on screen
- Maximize Readability
  - Choose fonts and backgrounds that enhance readability and perception
  - Enhance scanability with headers, bulleted lists, and tables
- Visual Treatment and Layout
  - Use sufficient 'white space' to separate sections
  - Avoid unnecessary animation and images
  - Use an appropriate graphic design (visual treatment)
- Supports User Actions
  - Design a navigation scheme that helps users determine next steps and anticipate action results
  - Provides a clear exit point
  - Use a simple, clear structure
- Prevent Errors
  - Don't allow invalid options to be used
  - Assist the user in recovering with:
    - Error messages in plain language
    - Error messages describe action necessary to correct them

- Provide Shortcuts
  - Provide access to key functionality from all screens
  - Provide hot keys to increase data entry speed
- Support Learning
  - Support new users in completing tasks
  - Provide step-by-step instruction for complex tasks
  - Help users learn advanced functions
- Provide User Assistance
  - Use informative onscreen prompts
  - Adapt the interface to match context
  - Ensure that help is always available
- Be Reliable
  - Provide correct information and results



## 7. Appendix C: Raw Data

The raw data for this evaluation is split over several files. See the table below for specific details.

Data	Source file	Comments
Survey results	Excel file with 3 worksheets	Duplicate and spurious responses were removed. E.g., one culled response only completed the first question. Another culled response contained swear words and complaints about being forced to complete the survey by a teacher.
	RAW DATA worksheet	The top row contains filters that can be used to restrict the view to specific responses based on a criteria.
	TABULATED RESPONSES worksheet	Summaries of each question in table form.
	TEXT ANSWERS worksheet	Free response collections.
Web hits	Excel file	One page. Shows the most frequently visited pages in September 2003.
Search box entries	Excel file.	Over 6000 rows. Reflects the search box entries between Jan 1, 2003 and Oct 31, 2003.
Webmaster queries	Word document	124 entries. About 20 pages printed in landscape mode using a small font (Arial 8pt). The rightmost column contains the categorization added to the entries during the evaluation.
Interview notes	Word documents, one per interview.	Raw notes of the interviews. Each between one and two pages long.

To obtain copies of the raw data files contact:

Larry Thompson (Chief, Communications and Public Liaison Branch)  
Phone: (301) 594-0954  
E-mail: thompsl@mail.nih.gov

### Next Sections: Data

The following pages show major portions of the data listed in the table above. Data that could not be formatted reasonably for printing (the complete excel sheet of the raw data from the survey) or would have been excessively long (all 6548 search box entries) were not included.

## Survey Results Tabulated

<b>Total number of responses</b>	<b>161</b>	basis for percentage calculations below
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<b>1. How often do you visit genome.gov? Please select <u>one</u> of the following:</b>	<b># of responses</b>	<b>% of total responses</b>
This is my first visit	94	58%
Once every few months	15	9%
Monthly	7	4%
Weekly	27	17%
Daily	10	6%
Spend most of the day on it	3	2%
No response	5	3%

<b>When visiting genome.gov, what information are you usually looking for? Please select all that apply:</b>	<b># of responses</b>	<b>% of total responses</b>
Latest news about genetics and genomics	91	57%
Human Genome Project	82	51%
General scientific information about the genetics and genomics	51	32%
Ethical issues surrounding genetic and genomic discovery	45	28%
Educational materials (K-12)	40	25%
A specific medical or health condition	39	24%
Genetic testing	31	19%
Funding and research opportunities in my field	22	14%
Scientists and people who work at NHGRI	24	15%
Training opportunities	23	14%
A specific gene	23	14%
Seminar and event schedules	21	13%
Employment opportunities	16	10%
Proposal and grant submission guidelines	13	8%
Permissions for using materials from genome.gov	10	6%
Other (please specify) - see Text Answers worksheet	24	15%

<b>3. Did you find what were looking for today? (or on your last visit if you are just arriving on the site today)</b>	<b># of responses</b>	<b>% of total responses</b>
Yes (please go to question 4)	87	54%
No (please go to question 5)	26	16%
Not sure	37	23%
No response	11	7%

4. If Yes, what helped you find the information? (please select all that apply)	# of responses	% of total responses
The headings were clear	52	32%
The site was easy to navigate	41	25%
Information was in the category I expected	39	24%
The search box	36	22%
The site index	23	14%
Someone sent me a bookmark or direct link to the information	9	6%
Other (please specify) - see Text Answers worksheet	7	4%

5. What, if anything, do you find confusing about the Web site?	See Text Answers worksheet
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6. What features or pages have you found useful?	See Text Answers worksheet
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7. Does the current genome.gov site meet your needs?	# of responses	% of total responses
Yes	79	49%
No, with reason specified - see Text Answers worksheet	15	9%
No response	67	42%

8. In what role are you using genome.gov today? Please check the <u>one</u> that best applies.	# of responses	% of total responses
Student - secondary (middle or high school)	24	% not included since there were so few responses
Student - college/graduate school	11	
Educator	4	
Health care provider (e.g., physician, nurse)	1	
Public health group representative	1	
Patient with a specific disease or condition	1	
Family or friend of a patient	0	
Researcher/Scientist	8	
Funding (grant) seeker	2	
Librarian or information professional	0	
Interested citizen	6	
News reporter/media person	0	
Job seeker	2	
Policy analyst	0	
NHGRI employee	0	
NIH employee	0	
Other (please specify) - see Text Answers worksheet	9	
No response	101	63%

9. Which of the following categories includes your age?	# of responses	% of total responses
Under 18	38	24%
18-24	29	18%
35-49	25	16%
25-34	22	14%
50-64	22	14%
65+	4	2%
Rather not say	7	4%
No response	14	9%

10. Which of the following best indicates the highest education level you have completed?	# of responses	% of total responses
Current middle or high school student	25	16%
High school	5	3%
Some college or vocational school	5	3%
College degree	11	7%
Graduate/professional degree	17	11%
Other (please specify) - see Text Answers worksheet	0	0%
No response	91	57%

11. How long have you been using computers?	# of responses	% of total responses
5 years or more	120	75%
3 - 5 years	11	7%
2 - 3 years	6	4%
Less than 1 month	3	2%
1 - 2 years	3	2%
1 - 6 months	2	1%
6 months - 1 year	2	1%
No response	14	9%

12. How often do you use a computer?	# of responses	% of total responses
Several times a day or most of the day	80	50%
Every day	44	27%
Several times a week	14	9%
Once a week	2	1%
Several times a month	0	0%
Once a month	0	0%
Less than once a month	3	2%
No response	14	9%

13. How often do you use the Internet?	# of responses	% of total responses
Several times a day	84	52%
Every day	33	20%
Several times a week	17	11%
Once a week	5	3%
Several times a month	0	0%
Once a month	0	0%
Less than once a month	0	0%
No response	13	8%

14. Where is your primary Internet usage?	# of responses	% of total responses
Home	36	% not included since there were so few responses
Work	14	
School	5	
Library	1	
Public computer lab	4	
Wherever I am (laptop/PDA/Web-enabled cell phone)	5	
Other (please specify) - see Text Answers worksheet	0	
No response	91	57%

15. What Web sites do you visit regularly (from home or work)?	See Text Answers worksheet
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## Survey Results: Text Answers

2. When visiting genome.gov, what information are you usually looking for?
Other (free responses)
I found this site excellent* except I couldn't locate the copyright date of the pages I visited (when each page was written/last updated)* and this info. is essential for citation.
A research project.
I used to work there as a scientist* and now write for the general public about the project. Since they need to confront the ethical issues next* it would be helpful if the ELSI component was prominent on the page. I have
Anything that supports the fact that the genome project is a direct result from the Eugenic movement* the greatest US evil. The evil that was passed into law by unmoral scientist the only time in history that government was so
photographs
For a science abstract
Information on human genetics in general for presentations and for papers.
progress reports and when progress will be of help mankind. comments: Also* I think you should
sequence creatures who are long "lived" and ones who have the ability to regrow missing limbs. More than this*
I want to know what the study of genetics* the careers involved* and the the training involved
Curiosity's Sake
I am wondering if you are doing any research on Von Hippel Lindau Syndrome...my daughter* 11 has it..and i
found out that I have it as well...I am 43....thank you...
College psychology assignment
Something relating to the idea that we all come from one of 33 original females and that our genes contain a
record of our dispersal across the globe.
Any info on the use of gene chips to assess psychotherapy.
dna's 50th anniversary
Just my thinking about what the cattle are now-adays being fed (brains* spinal cords and lower intestine} has
turned me off about eating rib roast* frankfruters* sausage and baloney.
cloning techniques regarding Cloning/Embryonic Stem Cells
modification of oneself so others will live a better life and help all man kind
ENCODE data
Chromosome 8 information
Information concerning the chicken genome research
Social and Behavioral Research
research for school
government propaganda

4. If Yes, what helped you find the information? (please select all that apply)
Other (free responses)
The change from [nhgri.gov] to [genome.gov] was a good choice.
The search utility is very limited.
nothing trial and error
news story
GENOMICS AND DISEASE PREVENTION UPDATE VOLUME 11* No. 24 December 11* 2003
google search led me to the proper page
free educational materials but the problem is i cant download web lectures which are actually free

5. What, if anything, do you find confusing about the Web site?
screen size
not too much
There is nothing confusing
Hard to find people and full contact info
everything
It would be more helpful if it included a paragraph or two about the ELSI issues.
Layout; poor search engine.
whether the genetic sequence can be changed to replace someone's glitched DNA* to make them healthier
the facts that were given
The way that the pages are numbered. I am wondering if they could be labeled by topic area.
The order of the diseasesand the list you provide
Text heavy* layout is a bit busy
The website did not contain the information I was looking for.
Nothing
What's a genome?
nothing because I wasnt looking for anything just browsing
Other than sequencing of a genome* there are some times landmark happenings in functional genomics. These don't get 'visible' place on News channel of the site.
not much direct information available
Lack of hyperlinks on Breaking news
Putting GARD over to teh side when I am looking for disease info
everything was confusing
nothing
i didn't find anything on the genetic disorder that I have...
bio.com announced that the Pan Troglodytes genome sequencing had been completed and details on the comparative genomics were available on your website. It's not anywhere I can find.
Not your problem....I'm not sure what to look for.
It's a great website* you just don't happen to have the condition info I was after
Locating NHGRI Staff Information. There should be a irectory page enabling one to view the staff name* e-mail* tel* bldg. number* title* etc...
Nothing confusing - you just don't have what I'm looking for. Info on the use of gene chips to assess
nothing
none
It was difficult to determine (without a great knowledge of genetic terminology) what the status of the genome project was... I read a book that suggested that 50 years would pass before it was completed and wanted to
When you search in the search box in the choices you get* the words that you searched for are not pointed out in any way. That would help out a little.
im not sure what to look for when im looking for what the chromosome does.
you cant ask questions
I wanted to find the code* whatever it may be. I could not eaisly find it.
vocabulary
The ELSI email was not working* had to call.
nothing
proes and cons of human genome project
what does it all mean?!?!?!?!?

6. What features or pages have you found useful?
easy navigation* clear headers
health information
most of the ELSI information Summaries of certain programs* especially the HGP
Yes* i have to do a project for science and this web site is very useful!!
The 3 heading on the front page are good.
nothing
I can get into GenBank without being stopped by the journal subscription requirements. This site has been the only way the general public can get into the information without a subscription. I know the journals
the video in the educational site* the HGR site* all of your information has been extremely helpful* especially the info on Crohn's Disease in the genome sequence
There are links to various other pages. The website is comprehensive.
List of sientists Newsroom Calendar
Pictures and presentations are very useful.
Don't know
cancer.gov site genome.gov site
What's a genome?
No special comments. But 'features' have the tag of credibility* no doubt.
information pages
Humane Genome map
search
the information when you first come in
gene disorders
Home page.
Home page.
Homepage
Educational materials*Human Genome Project
The genes page
search...
The glossary of terms* in addition to the specific links at the bottom of each page* allowing me to receive information more specific to what I was looking for. This is a very well maintained website.
human genome project
descriptions easy for understanding why?We need to reverse medical and health impairments in our dna(imperfection in our mutated higher reproductive cells)genetic corrosion & cell memory fatigue
The new news feature was good.
clarity of site -- ease of finding needed data without going through layers of pages
the Researchers Resources with other helpful links
lots of information
genom information
pages on Parkinson's Disease
It has interesting infromation on it which expands my background knowledge on genetics and helps in my biology
the home page search
Two links: GARD Information Center is superb. National Library of Medicine's Genetics Home Reference is excellent. Also appreciated the staff bios with picture* locating info and research interests summary: great.
news*educational materials
search box* site index
the biright colours
Genetics FAQ
the FAQ
Genetics FAQ* search box



### 7. Does the current genome.gov site meet your needs?

I need basic facts.  
its confusing!  
See previous comments.  
Search engine poor.  
The site is full of propeganda that makes the Genome project seem like something that will help humanity at  
Couldnt find who article was written by  
The site does not contain the information that I need.  
First time searching  
there is not enough information for me to write three pages on  
I would appreciate if a matrix table including the common name\* species name\* # of chromosomes or pairs\* # of genes\* # of base pairs\* and any reference locations to get more detailed information could be presented for  
No Info on the use of gene chips to assess psychotherapy.  
Hard to find specific info. Only general info or overly complex stuff to browse.  
i have yet to find my information  
there are no informations on bioinformatics  
Just looking for the code

### 8. In what role are you using genome.gov today? Please check the one that best applies.

Other responses  
Interested non-citizen (i.e. not from USA)  
lay advocacy group leader/nonprofit professional  
USDA employee\* Veterinarian  
Psychotherapist and author of "The Psychobiology of Gene Expression" (W. W. Norton Professional Books\*  
i have charcot marie tooth disease type 2  
self education awareness  
Concerned citizen about our food supply and the way our government is being run. After doing much reading  
feel the USA has been much too lax in record keeping\* etc.  
an interested citizen comparing the real life process of todays science in comparison to storylines in a fictional  
story. Which in my opinion has done a great job keeping in context to the research.  
Attorney representing a child who has been ordered to undergo genetic testing

### 10. Which of the following best indicates the highest education level you have completed?

Other responses  
PHD  
PhD  
post doctoral level  
I am currently covering a college biology unit\* and am at the college level in most of my studies\* although I'm a  
Ph.D in clinical psychology  
medical Genetics  
MD/PhD

14. Where is your primary Internet usage?
Other responses
every where
homeworkig
play the stock market and visit with my loved ones via email
Research in topics of interest* which vary widely.
university

15. What Web sites do you visit regularly (from home or work)?
Other responses
www.cancer.gov www.nytimes.com www.washingtonpost.com
Google Washington Post New York Times Wall Street Journal other news sites Science Nature The
www.cnn.com www.ebay.ca www.electronicintifada.net
bmn.com
yahoo google NHGRI BBC News
google.com Human Genome sites Science Magzine sites
Sites 4 HW
NIH
www.google.com or www.aj.com
i use AIM (aol.com) and i go to azlyrics.com al0t
Washington Post New York Times an Francisco Business Times South China Morning Post L.A. times London Times Japan Times San Francisco Chronicle
www.bellsouth.net www.ask.com www.yahoo.com www.recipesource.com www.visionsaturday.com
google.com ask.com
CNN Weather.com
ncbi google dictionary.com gene ontology
goggle.com genome.gov NHGRIInside (Assignment Desk)
I visit websites that pertain to what I am studing in school.
My own
Yahoo news Google news Science news daily BBC
genome.gov cancer.gov cdc google for searching
www.hotmail.com
the journal Nature any sight that deals with phylogeny or taxonomy
http://home.austarnet.com.au/stear/default.htm http://members3.boardhost.com/john666/ http://www.talkori
www.msn.com www.yahoo.com www.earthlink.net
USDA sites e-bay health natural foods
Besides NCBI and EBI (For Bionformatics tools and databases) I have to blaze around lots of News resources on web for genomics-from Eurekalert to GNN to Betterhumans.Being Genomics and Bioinformatics information sites about biology msn what catches my fancy mainly
www.google.com
google
things
cheacc.com
VHL Alliance site...
www.hotmail.com www.yahoo.com www.nhgri.nih.gov/ www.mapquest.com
NCBI google
science.com;sciencedaily.com;nature.com;sciencenews.org
Google Yahoo AccuWeather numerous job related sites

google
genome.gov www.clonaid.com
www.vhl.org sites relating to my occupation (holistic vet) music sites my email sites
www.elfwood.com and I check my e-mail on yahoo.
google
bbc mugglenet.com hotmail yahoo
research
Science Nature PNAS journal sites.
chicken@bob.ear
nih.gov nutrition.gov pubmed.gov
www.ahrq.gov www.reuters.com
science & astronomy
sdccu.net; nytimes.com; equilter.com; constructionmail@construction.com; southwest.com;
volcoordinator@sandiegoaudubon.org; theworld.org; californialung.org; drkoop.com; heavens-above.com;
www.nigms.nih.gov
yahoo
yahoo
Yahoo
www.usda.gov www.europa.eu
work: primarily use internet to gain information on grants/grant submission guidelines etc. for nursing school in the Texas Medical Center NIH grant home pages various individual Institute pages State of Texas grant explorer
ask.com jeeves.com
email web sites
google
x-factor human enhasment
new england journal; up-to-date;
Testing.... (this is zeki)
aol yahoo google ncbi.gov
spacefed.com google.com bored.com swirve.com vampfreaks.com gothicbeauties.com
ncbi.nlm.nih.gov/entrez (and other pages at
NCBI) www.ebi.ac.uk us.expasy.org www.yeastgenome.org/ yahoo.com google.com
www.bbc.co.uk www.google.com www.learn.com www.funkydragon.org www.puzzledonkey.org
Anything to do with Multiple Sclerosis
www.ncbi.nlm.nih.gov
www.msn.com; www.apple.com
cnn.com hotmail.com ebay.com wired.com
email
various science ones mostly web of science
www.hotmail.com
Google Yahoo Girl's Life
www.genome.gov site like that

**Top pages (September 2003)**

<b># Hits</b>	<b>Page</b>
52576	Home
21451	Education Kit
19874	Glossary
9499	Site Search
9584	Genomic Research
7535	Spanish Glossary
5590	Staff Search
5383	Education (Tier 2)
5323	Course 2003
4616	Research (Tier 2)
3404	Elsi Research
3001	About the Human Genome Project
2829	Mentorship Database
2791	Learning about Genetics (Health)
2369	Specific Genetic Disorders
2359	Policy and Ethics (Tier 2)
2283	International HapMap Project
2246	About (Tier 2)
2208	Careers and Training (Tier 2)
2089	The Future of Genomics (PDF Download)
2087	Health (Tier 2)
2074	The Future of Genomics (HTML)
1825	Grants (Tier 2)
1794	News Room (Tier 2)
1442	Research @ NHGRI
1356	April 2003 Celebration
1351	Privacy, Discrimination and Legal Issues

**Search box entries from Jan 2003 - Sep 2003**

<b># of occurrences</b>	<b>search box entry</b>
100	testing and treatments
88	homeodomain
86	microarray
70	glossary
61	human genome project
60	cloning
58	progeria
45	gene therapy
44	DNA
37	dog
37	cystic fibrosis
37	aids
34	polydactyly
31	sickle cell anemia
28	human genome
28	genetic counseling
27	genome
24	dna
24	cancer
24	Parkinson%27s&path
24	Human Genome Project
22	stem cells
22	gene
21	chromosome
21	ELSI
20	pictures
20	BIC
20	10000884&searchString
19	genetic engineering
18	stem cell
18	race
18	homeodomain protein
18	collins
17	nih director
17	breast cancer
16	homiodomainprotein
16	chromosomes
16	brca1
16	SNP
15	obesity
15	history
15	SCID
15	RNA
14	retreat
14	internship
14	haplotype
14	Progeria
13	schizophrenia

13	mitosis
13	microarrays
13	images
13	homiodomain protein
13	hemochromatosis
13	gene mapping
13	Francis Collins
12	white paper
12	stem cell research
12	rna
12	reproduction
12	genetic testing
12	genes
12	ethics
12	chromosome 22
12	allele
12	HOMEODOMAIN
11	tissue array
11	timeline
11	human cloning
11	down syndrome
11	biodefense
11	DNA sequencing
11	CGH
10	translocation
10	publications
10	map
10	hemophilia
10	chromosome 1
10	HGP
10	BRCA1
9	what is the human genome project
9	tay sachs
9	mutations
9	karyotype
9	glossary of genetic terms
9	genome project
9	genetics
9	francis collins
9	elsi
9	dwarfism
9	dog genome
9	dictionary
9	bic
9	Glossary
9	ADHD
8	zebrafish
8	xenotransplantation
8	transcription
8	technology transfer
8	pku

8	mutation
8	meltzer
8	melanoma
8	mapping
8	insulin
8	illustrations
8	hiv
8	goals
8	genetic screening
8	eye colour chromosomes
8	eugenics
8	disapprove
8	developmental genes
8	clone
8	alkaptonuria
8	HapMap
7	transgenics
7	technology
7	tRNA
7	summer internship
7	sickle cell
7	protocols
7	polymorphism
7	phenylketonuria
7	parkinson%27s disease
7	parkinson
7	northern blot
7	muenke
7	implications
7	huntington disease
7	homiodomainonlinereserch
7	genoma
7	genetic mapping
7	funding
7	fragile x
7	ethical issues
7	diseases
7	chromosome 7
7	cell
7	bipolar disorder
7	austin
7	achondroplasia
7	PKU
7	FISH
7	Collins
6	trisomy 13
6	the human genome project
6	thalassemia
6	smith magenis syndrome
6	scid
6	recessive

6	rRNA
6	protein
6	propecia and prostate cancer
6	primer
6	patents
6	parkinson%27s
6	opossum
6	number of genes
6	nanotechnology
6	muscular dystrophy
6	marfan syndrome
6	marfan
6	huntingtons disease
6	hepatitis c
6	hapmap
6	genotipo
6	genetic disorders
6	genetic discrimination
6	evolution
6	dna sequencing
6	dna fingerprinting
6	diabetes
6	candotti
6	arrayviewer
6	anzick
6	alu
6	alcoholism
6	Y chromosome
6	What is human Genome Project
6	The Human Genome Project
6	PCR 30
6	HUMAN GENOME
6	Down Syndrome
6	DNA fingerprinting
6	CEGS
5	workplace
5	white papers
5	what is human genome
5	what is a genome
5	western blot
5	virus
5	video
5	unigene
5	turner syndrome
5	tourette
5	tay-sachs
5	spina bifida
5	social issues
5	sex chromosomes
5	proteomics
5	protein synthesis



5	prostate cancer
5	poster
5	physical map
5	phenotype
5	pedigree
5	parkinsons
5	neurofibromatosis
5	mus musculus forkhead box N1 %28Foxn1%29%2C mRNA
5	meiosis
5	mcbride
5	kate berg
5	jobs
5	irb
5	illustration
5	homozygous
5	hgp
5	heredity
5	haplotypes
5	genotype
5	genetic diseases
5	from maps to medicine
5	founders
5	fenotipo
5	eric green
5	employment
5	duplication
5	download
5	dominant and recessive genes
5	dna replication
5	disease
5	deletion
5	database
5	cost
5	color blindness
5	chimpanzee
5	cgh
5	central dogma
5	cDNA
5	brca2
5	bonham
5	biotechnology
5	bioinformatics
5	autism
5	aging
5	advantages
5	adhd
5	PCR
5	PATCH GENE
5	PAF-AH
5	Molecule of DNA

5	IL2RGbase
5	Genome
5	Genes
5	ENCODE
5	DNA fingerprint
5	ADN
5	8778
5	2003
5	homedomain
4	zenklusen
4	yeast
4	y chromosome
4	x chromosome
4	what is the human genome
4	what is human genome project
4	what is gene therapy
4	trisomy
4	transfection
4	tools
4	thymine
4	talking glossary
4	sponsors
4	spanish
4	shotgun
4	sequencing
4	ribonucleic acid
4	red flour beetle
4	priority
4	prenatal testing
4	pig genome
4	picture
4	p53
4	oncogenes
4	news
4	mouse genome
4	monascus
4	microarray facility
4	microarray database
4	mRNA
4	lymphoma
4	lung
4	locus
4	kallioniemi
4	junk dna
4	junk DNA
4	initial sequence
4	in situ hybridization
4	huntingtons
4	huntington%27s disease
4	human genome map
4	homosexuality

## Webmaster queries March 2003 – July 2003

Webmaster query	Categorization
Good stuff on your website BUT....when was it published? revised? Is this material as current as possible? How would I know since there is no date noted anywhere? Please... do yourselves a big favor and learn to put the date of publication/revision on each item within your website. It would help those of us who are attempting to keep up with current and credible material, and it would make you look soooooo good. (Mrs.) Marianna Fettes Library Technician Consumer Health Information Service 789 Yonge Street Toronto ON sfettes@tpl.toronto.on.ca	Content suggestion
Hi! My name is Cami Krier. I am from Port Orchard, Washington. I am in 8th grade and we have an opportunity to be a job shadow. I am really interested in genetics. I have learned a little about genes in my Life Science class, but I would REALLY like to learn more. So, I was wondering if you had an institute in the Puget Sound area, like Seattle or Tacoma where I could possibly be a job shadow. Our date at Cedar Heights Junior High for the job shadow day is on May 21st, and our registration form is due May 19th. So if you could get me any information, I would appreciate it as soon as possible so I don't miss this great opportunity. Thank you for your time. Sincerely, Cami Krier Port Orchard, WA	Content suggestion
Is there any one place that I can access the incidence rate of genetic diseases? Many thanks, Tracey Novick.	Content suggestion
I work in criminal defense and have a question regarding DNA tests. How close or similar is the DNA among triplets? Is there a potential for the results to be inconclusive as a result of very similar DNA?	Content suggestion
I was wondering how long in basepairs is the average human gene, and how long in basepairs is one centimorgan for humans.	Content Suggestion
I would like to know if a database has been established to exclusively house the canine sequences yielded from the Whitehead Institute of recent or if they are simply being deposited into GenBank.	Content suggestion
If I would like to volunteer to have my DNA studied how would I go about doing so?	Content suggestion
I would be very grateful if you could give me a rough estimate of the number of haplotype blocks human genomes are thought to contain, and whether or not this is seen as typical of other species as well.	Content suggestion
Dear Sir or Madam, As a professional translator from English into French, I am currently working on an essay about the HGP published after the completion of the rough draft of the sequence, but before the completion of the final sequence in April 2003. In order to solve some problems in the text, I would need to know the current American estimates (after completion of the full sequence) for the number of genes contained in the human genome. I am also desperately searching for information about the number of cDNA samples a human DNA microarray is comprised of. I would be very grateful if you could provide accurate information about these two points, as I have been doing quite a bit of research and haven't been able to find satisfactory answers... Thanks in advance for your help! Yours sincerely BH	Content suggestions
My company, K12 Inc., is developing a life sciences curriculum for middle and high school students. I am interested in learning how we might be able to incorporate educational resources from the National Human Genome Research Institute into our lessons. Our curriculum is internet-based and is delivered over a secure, password-protected website that is available only to subscribers. We are particularly interested in the 3-D animation of DNA that is included in the multimedia CD-ROM "Exploring our Molecular Selves." Could you please put me in touch with the right person to discuss terms for licensing clips or stills from this animation? Thank you for your kind attention to my request. Sincerely, Sally Russell Multimedia Producer K12 Inc. 703-970-8216 srussell@k12.com	Educational collaboration

My name is Jolene Nakao, Research Analyst for the Center for Health Improvement (CHI), a nonprofit, nonpartisan health policy and prevention research center based in Sacramento, California. I am writing ask if you know of any educational video on the following topics: Angelman Syndrome Autism Cerebral Palsy Congenital Rubella Syndrome Cornelia de Lange Syndrome Down Syndrome Duchenne Dystrophy Fetal Alcohol Syndrome Klinefelter Syndrome Landau-Kleffner Syndrome/Acquired Epileptic Aphasia Neurofibromatosis Type 1 Noonan Syndrome Phenylketonuria Prader-Willi Syndrome Rett Syndrome Smith-Magenis Syndrome Trisomy 18 (Edwards Syndrome) Tuberous Sclerosis Turner Syndrome Velocardiofacial Syndrome Williams Syndrome XYY Syndrome Psychiatric Co-morbidity (with developmental disabilities) Tardive Dyskinesia The Center for Health Improvement maintains the Developmental Disabilities: Resources for Healthcare Providers website, located at <a href="http://www.ddhealthinfo.org">http://www.ddhealthinfo.org</a> . The website was created to improve the health of persons with developmental disabilities in California by educating physicians and other health care professionals concerning care for this population. The site also supports persons with developmental disabilities and their families in making informed health care decisions. We are planning an expansion and enhancement of this website during 2003-2004. In the Index of Clinical Practice Considerations under the Developmental Disabilities Digest section of the website, 51 documents on conditions and issues associated with developmental disabilities are posted, including pieces on Autism, Fetal Alcohol Syndrome, Spina Bifida, and Fragile X Syndrome, to name a few. As part of the enhancement, we plan to add a 5-minute video component to each of a number of these documents to visually illustrate characteristic features of certain conditions. An example of the kind of video we'd like to add can be found on <a href="http://www.ddhealthinfo.org/ggrc/doc2.asp?ParentID=3169">http://www.ddhealthinfo.org/ggrc/doc2.asp?ParentID=3169</a> , complementing the document on Fragile X Syndrome. We are interested in posting simple, 5-minute video clips to illustrate the above-listed conditions beside the corresponding documents on this website. In exchange, the video producer/owner will be acknowledged in his/her work to assist others in learning about the condition. If you know of a video of a greater length, it would be no problem for us to edit it down in size. The video clip can also serve to introduce the video to interested parties. I would love to hear from you if you have any video or know of an organization that does. We look forward to working with your organization to provide the best health care for people with developmental disabilities. Sincerely, Jolene Nakao	Educational collaboration
FYI, Your audio in the glossary does not work, even with the high speed connection we have here	Error
I meet a gentleman named Mark Hilliar this past week. Mark gave me his e-mail mhilliar@nhgri.nih.gov. but when I try to send an e-mail to him, I am getting a fatal error on his e-mail address, could you please send me his correct e-mail address? Thank you, John Flewellen	Error
SIU link seems to be broken. I enter a username and password and it dumps me back to the NHGRIInside homepage. I am using a Mac (OSX) and the Safari web browser	Error
I cannot get the audio detailed descriptions to work. My REAL Player is working fine for all other purposes. Please help. Thank you.	Error
This website is a GREAT resource. My question is: Are the transcripts of the audio clips in the talking glossary available to the public? My work computer does not have a sound card, so I am unable to get the valuable information in the detailed audio explanations. I know how great they are because I checked some out from home, but I need to use this resource at the office! Thanks for any info you can provide.	error
Suggestion: It might be of urgent need to provide a site for non scientists, that clarifies what a gene is and mostly what it is not, because a growing number of "scientific" studies claim to find links between genes and social behaviour, some are even trying to find genes for ethnic different social behaviour. Searching for a little more information about this nonsense, just found ethical refusals, which I endorse, but really think genome project had different aims in mind. Anyway, social Darwinism is growing on the expenses of the prestige of the genome project. My intuition leads me to think that "good" intentioned applied genetics can be as dangerous as "bad" intentioned one if these issues are not very fast cleared, for the wide public, in a time of raising ethnic hatred and nationalisms. The collective madness started in the thirties in Germany could not be avoided by intelligence only and some scientists played an important role on the spread of pseudo-scientific racism. On the other hand it's a known fact that criminals executed in Nuremberg had high IQs and probably none of them killed anyone with his own hands. They probably would have had the "right" genes according to our own present standards of "excellence" or "social fitness". I believe human being is much, much more than the genes will ever tell. Would be very nice to have this idea somehow worldwide confirmed by wise scientists. A worried sociologist teaching young people in Portugal	Ethical
With stem cells being not so easy to get for research. Has anyone ever thought of asking new parents upon the delivery of their child to donate the cord blood stem cells? Maybe even offer to store their childs cord blood free if the excess would be "donated" to researchers. We saved our childs cord blood and would have willingly donated the excess had someone asked. Just seems like a logical alternative to me. Sincerely, Cathy Wirth 9564 Springwater Lane Miamisburg, Ohio 45342	Ethical
Many years ago, when the Human Genome Project began, I saw a PBS special called "Children of Eve," or something to that effect. The program presumed that the Human Genome Project would answer this question: Are we all related? Has the project answered that question? If so, where do I find the information? If not, do you believe the project will answer the question? Is anyone working on such a notion? I find this concept to be the most compelling social notion of all time, so I would sincerely appreciate a response. I could not find such information on your website. Thanks, and Have Fun!	Ethical

<p>Hello, Recently I have been undergoing an extensive research project on genes associated with humans ability to communicate. I am wondering whether those involved with the Genome Project have found a series of genes involved in the ability to construct language and whether we have the ability to turn them "on" and off"? If so, do we have the ability to control what type of language or other form of communication results? I have read on the internet from a source I have not yet concluded reliable that chromosome 7 deals with communication. I am unsure and thought best to ask you, the experts. My research, in it's final stage, will be looking at the ethical implications in controlling genes and their production of communication and communication's ties to culture. I would be much obliged to receive any feedback in regards to genes involved with the construction of the different forms of communication and our abilities to control the languages or other forms of communications' structure. Respectfully, Grant Keaton</p>	Ethical
<p>Hi, I really know very little about the genome project... I read above that "This site provides users with information to help the public better understand genetics, genomics and diagnosed genetic disorders" I'm a 20 year old Atopic Eczema sufferer, and have had Eczema for well, 20 years. All I am told by doctors is that it is a genetic disorder. I would like to ask, does this mean that now all the human genes have been mapped, you can isolate the genes responsible for eczema and well, "fix" them? Or, how long do you think it would be until advances are made so that "fixing" genetic disorders is possible? a year? 50 years? I'm not asking for your professional care or medical advice - only whether the completion of the mapping of the human genome means that genetic disorders can be cured, or whether it just means we can point at the gene and say: "yes, that's what's causing it". Thanks, Kieran</p>	ethical
<p>Why is studying the dog genome important? I read in USA Today about that being the next animal to be mapped. Dogs are as far removed from humans as hippos are. Just because they have the same number of genes as us doesn't mean they are anything like us. And surely the differences between breeds is almost zilch. A boxer is as close to say, a labrador, as a Chinese person is to a Black person. You're not going to map all the breeds, are you? That seems silly since they are so close. Best, April</p>	Ethical
<p>I have a question regarding an event being held at the Natcher Conference Center on April 14th and 15th. I have just finished looking at the registration information, and I see that it is full. The overflow seating, I'm sure, is quite limited, which caused some concern on my part before venturing to complete the registration information. The question I have is this: my girlfriend and I, both aspiring molecular biology majors (Molecular Genetics and Biochemistry, respectively) at the Ohio State University. The form for registration asked which degrees are held, and since we are students, we obviously hold no degrees as of yet. I thought it safe to assume we would not have the opportunity to take one of the (overflow) seats of a more accredited listener, which is why I am sending this e-mail. If you could send back any information about if our attendance would be possible, or if not, how we might be able to receive the benefit of such speaker's knowledge in another way, it would be greatly appreciated. Thank you.</p>	Event
<p>Could you tell me if the Scientific Symposium (From Double Helix to Human Sequence) to be held April 14-15 and the Public Symposium (Bringing the Genome to You) on the morning of April 15 is going to be offered as a satellite viewing to the University of Nebraska at Kearney, Kearney, Nebraska. Thank you very much for your help. Connie Fie Department of Economics University of Nebraska at Kearney Kearney, NE 68849-4570</p>	Event
<p>The deadline for submitting an ELSI R01 proposal is June 1st, which is a Sunday. Is it acceptable to have a proposal arrive by Federal Express on Monday, June 2nd, or Saturday, May 31st?</p>	Funding details
<p>Could you please tell me how do I go about finding information on line for filing an ELSI grant with a dead line of June 1, 2003?</p>	Funding details
<p>Hi, I love your site--use it all the time! I have a couple suggestions for terms to define, since they do not appear in Webster, and are frequently used in scientific papers: diplotype haplotype I seem to recall that there was another place on your Web site to suggest terms for the glossary, but for some reason, I can't locate it. Thanks much, Jenny Wenger NIDCD</p>	Glossary
<p>suggestions for terms to add to glossary: hemizygous Punnett Square</p>	Glossary
<p>There are already many possibilities in the field of genetics, such as curing hereditary diseases and increasing our life span, and we've only just begun our research on the human genome. However, this has also brought up a great deal of controversy, such as cloning and genetically engineering our babies. What possibilities do you see in the next fifty years and what possible conflicts do you think could occur?</p>	Homework help
<p>wondering if you could send me any information or direct to any literature that could help me understand the Human Genome Project and its implications. Thankyou Catherine</p>	Homework help
<p>Have there been any major discoveries about the human genome other than completing the map of the human genome in the ninetieth decade? i.e., Discovering that only x% is needed to find a cure for disease or disorder. Or that you have completed other minor projects related to the Human Genome Project. If so, I would be very thankful if you could send me a summary of these discoveries/achievements or weblinks to websites that may enlighten me of these subjects. My thanks, Brandon Gray</p>	Homework help

Hello, I'm from Calamvale Community College and this term, in school we are doing the Rich Task topic, Science and Ethics Confer. My partner Ashleigh and I have chosen to research about Reproductive Technology and about the resurrection of the Thylacine. WE were both wondering if there is any information about the Reproductive Technology that would help us or if there was any one we could contact? WE hope you could contact us soon, thankyou. Yen Ashleigh	Homework help
March 11, 2003 Dear NHGRI, Hello, my name is Deirdre Gordon and I am a high school student at Pleasant Valley High School in Bettendorf, Iowa. I am doing a project about stem cells and I was hoping you would be able to answer a few questions for me. If you can't I understand, but will you please email me back so I know if I will have the information or not. Please try and get back to me by Thursday or Friday. Any further information that you can provide would be a great help. Thank you! Sincerely, Deirdre Gordon 1. Describe what your job is in relation to stem cell research. 2. How long have you been in this field? 3. What is the relationship between stem cell research and cloning? 4. How would current and pending legislations impact stem cell research and possible business ventures? 5. How might stem cell research impact the world economy? 6. What is your personal opinion about cloning and stem cell research? 7. How far do you think it is ok to go in stem cell research? 8. Do you think it is ok the clone entire humans? 9. What are your hopes and fears for the future of stem cell research 10. What is your opinion on letting the stem cells develop after the have been tempered with? 11. What is your opinion on destroying morulas that have been tampered with after 14 days? 12. What injuries and diseases could be helped or fixed by stem sell replacement? 13. How does stem cell replacement work?	Homework help
HELLO, MY NAME IS AMY MACKLEY AND I AM A STUDENT AT FREDERICK COMMUNITY COLLEGE. I AM WRITING A PAPER ON THE ISSUE OF GENETICS AND WEATHER THEY CAN AFFECT A PERSONS BEHAVIOR AND WAS WONDERING IF THERE IS ANY WAY I COULD GET SOME INFORMATION ON THE SUBJECT. THANK YOU. AMY MACKLEY	Homework help
I am currently conducting research on informational security for a college paper and was wondering if you could provide me with information regarding your IT/informational security policy (available to the public). I wasn't able to find it on your webpage. Thank you very much for any help you can give me.	Homework help
I am doing a debate and i need to know the main benifits of experiments on human genes are? if you could e-mail me back that would be great Thanks Thomas O'Donahoo	Homework help
In school were are learning about herity and your cells. And my teacher told us about what this program is about. I think it is a really great thing and could lead to the prevention of many illness such as cancer and other life threatening dieases. I have a 2 questions though. When do you think this project will be finished? And do you think people will take advange of this too much and try to have a perpect child or anything like that? I can't wait to read the response and I will tell my teacher any infromation I recieve.	Homework help
can birthdefects change bone structure and make one look diffrent in the face,hands,feet and so on and so on. and if so could this happen to monkeys? i know this is a odd question but it is for a paper i'm writing and i need just need to know!!	Homework help
Hi, I am a young college age guy( united states resident) and I'm interested in genetics and would like any literature that you have. Thanks, Brad	Homework help
Should the results of the Human Genome Project be sold for profit and why do you think it should or shouldn't be sold for profit?	Homework help
Who are the appropriate points of contact at NHGRI that either recommend or purchase networking hardware equipment and cables for the agency? I work for CABLExpress the newest vendor on GSA for these products and would like to contact the right people at you agency.	Homework help (sort of)
I am a law student (UC Hastings) currently doing research for a PBS television and education project about the basic challenges genetic and reproductive technologies make to our notions of what it means to be human, to be a parent, and to inhabit our bodies. Noel Schwerin of Backbone Media (a California 501(c)(3) nonprofit) is producing the documentary (called BLOODLINES: Technology Hits Home), a Corporation for Broadcasting-funded Web site, and a substantial outreach and education program. I am helping to develop the Web site which will include a map of state and federal laws (including court precedents) related to 1) reproductive technology and parenthood, 2) genetic technology, genetic testing, discrimination and privacy, and 3) life creating technologies and patents, stem cells and cloning. I have seen your we site at: <a href="http://www.genome.gov/page.cfm?pageID=10002339">http://www.genome.gov/page.cfm?pageID=10002339</a> . I would like to know how accurate this web site is. It indicates that it is last updated April 2002. Has there been any additional employment discrimination laws enacted since then? Can you please tell me what states have enacted new legislation. Where can I go to find an updated summary of state laws? Thank you in advance for your help. I will follow up within the next two weeks. April Alex Backbone Media 58 Harper Street San Francisco, CA 94131 415.282.5620 ph 415.282.0230 fx aprilmalex@yahoo.com schwerin@backbonemedia.org www.backbonemedia.org	Homework help (sort of)

We're intrested in your works on the human genome project, and request that you assist us with resource and study aid materials,to enable us as medical students and doctors that are into the study of human genetics. we're in need of your aid in provision of software materials-CD roms and other related materials to enable us make headways. Also send e-mail contact to my colleague:iremchimex@yahoo.com,brightschimex@yahoo.co For snding of the above CDroms,please use: Irem chimezie Bright c/o the provosts office university teaching hospital pmb 053 Abakaliki Ebonyi sate Nigeria. with kind regards and hope for postive contacts.	Int'l – need resources
Dear Sir/Madam, I am computer specialist from India doing research on the available software tools that come in use in the field of genetics. I intend to specialize in developing software tools for the biotech and gene related bio sciences. I am writing this email to ask your guidance in knowing which tools are used by your organizations for research purposes. I would be gratefull if I could be involved in any way in creation of software tools for the genome projects. Regards, Himanshu Sharma	Int'l – need resources
Dear gentlemen. My name is Marco Aurélio Echart Montano, I am chemical and master in biotechnology, work in the University of Ijuí state of Rio Grande do Sul, Brazil. would like to request the donation of genetics books and molecular biology, because my wage as technician in the University is of U \$670,00 monthly, my address is; Rua do Comércio Nr. 2195 Ijuí - RS ZIP CODE: 98700-000 BRAZIL Respectfully Marco Aurélio Echart Montano.	Int'l – need resources
I am an undergraduate student of medical college. I want detailed information about PCR, its technique etc. What are polymerases, splicing, TAQ polymerase. We do not have access to or resources to purchase costly books, please help	Int'l – need resources
I am the Manager of Scientific Programs for CURE, we are a non-profit educational organization and provide teacher professional development workshops over the summer. We like to teach the educators about career opportunities in medical research. The Job Descriptions I have collected over the years have gotten out of date and I was wondering if you or if you knew of another organization that had sample job descriptions that educators could have to better advise their students as to the path they should take. Any help is appreciated. Thanks.	Job posting
As President of a Consortium on Cancer Research (CARSO) in Bari, Italy, I would like to advertise 3 positions for PhDs with postdoctoral experience and research interests in genomics and proteomics applied to cancer research. Could you please let me know if this is possible through your Institute. Thank you. Best regards, F.P. Schena, MD Professor of Nephrology	Job postings
I am a pathologist with Mayo Clinic. I am looking for a position at the National Human Genome Research Institute. I just need alittle assistance in finding a suitable position. Please contact me. Thank you. David J. Wolfson, MD wolfson.david@mayo.edu	Lazy
Dear Sir or Madam, I am writing to see if your organization would consider linking to ours as a resource for information on stem cell research. It is the goal of the Stem Cell Research Foundation to find treatments and cures for a wide range of diseases by supporting innovative research into the development of cell therapies. The link to our home page is <a href="http://www.stemcellresearchfoundation.org">http://www.stemcellresearchfoundation.org</a> . If you have any questions, please do not hesitate to contact me by email at <a href="mailto:PublicEd@stemcellresearchfoundation.org">PublicEd@stemcellresearchfoundation.org</a> or by calling 1-877-437-2423. I look forward to hearing back from you. Best regards, Ed Berger Manager of Website Operations	Link to request
How may I find out if Dr. Francis Collins would be available to give opening remarks at a New England Regional Symposium for Nurses on Genetics at Northeastern University in Boston MA. September 13 2003? The purpose of the day is to train nurses throughout New England as trainers to teach others in their work settings about genetics. Thank you so much for your assistance. Regards, V.Minichiello	Locate individual
Please advice Dr. Michael blase that his definition of gene therapy was eloquent and his research efforts on behalf of the genome pool is exemplary. The spelling of the word "inherited" needs a little work. Meticulous in Michigan, D.R. McCarthy p.s. I wish you continued success in your work.	Locate individual
DR. GEOFF SPENCER: The Universidad del Rosario, from Bogotá-Colombia is trying to contact Dr. Francis Collins to invite him as Speaker in a conference celebrating our 350 years of foundation. Could you please, give us his mail, fax or telephone numbers where we can reach him. We will be gratefull to receive this information at your earliest convenience. Cordially yours, MARIA VICTORIA FORERO Assistant to Rector	Locate individual
hi i would know if there is any way to download the DNA animation and the other animation found at the web site .iam a medical studet preparing a presentation about the DNA and the gene mutation . i will be pleased if you can tell me how to download them .thank you	Permission and access

My name is Sara Cartee and I am a BSW Intern for CuraScript Pharmacy in Orlando, Florida. We are currently updating our company website, <a href="http://curascript.com">http://curascript.com</a> , and are in the process of developing an On-line Resource Guide for our patients' use to be included under Patient Services. Due to the valuable and pertinent nature of the data available through your website, we would like to include information and a link for the National Human Genome Research Institute as part of our resources. I would like to request permission to attach such a link and I would require written consent for confirmation in the form of E-mail, letter, or fax. Can you provide me with the permission to link or, if not, provide me with the appropriate contact to attain such authorization? Electronic responses may be E-mailed to <a href="mailto:sara.cartee@curascript.com">sara.cartee@curascript.com</a> and faxes and letters may be sent Attn: Sara Cartee to 888-773-7386 or the following address: CuraScript 7101 TPC Drive, Suite 150 Orlando, FL 32822 Thank you for your time and consideration, Sara Cartee, BSW Intern	Permission to link to genome
I teach Microbiology at Frank Phillips College in Borger, Texas. The college has a website and I have a page on that website. Is it permissible to link your site to my course page? We are doing a biography project focusing on the 20th century pioneers of the DNA revolution to celebrate this anniversary. This website could be a real help to my students doing their research. Thank you, G.M. Morris Biology Instructor Frank Phillips College	Permission to link to genome
I would like to ask for Your kind permission to let me reproduce the picture at: <a href="http://www.nhgri.nih.gov/DIR/VIP/Glossary/Illustration/protein.html">http://www.nhgri.nih.gov/DIR/VIP/Glossary/Illustration/protein.html</a> as part of my thesis while taking care of any requirements you would like on how to refer to your work on that. Sincerely Johan Unge	permissions
Dead Webmaster, You have a wonderful Talking Glossary, and I especially like the illustrations - very clear and informative. I am currently writing my PhD thesis on computational prokaryotic promoter recognition and I need to include illustrations of the basic concepts from molecular biology I'm going to use in the text - what is DNA, RNA, nitrogenous bases, complementarity principle, etc. May I ask your permission to use some of the illustrations from your web site in my thesis? Thank you very much in advance, Leo.	permissions
How do I cite an NHGRI report? I know the URL, but I cannot locate a report number, as would be required in an official citation. The report of interest is: Developing a Haplotype Map of the Human Genome for Finding Genes Related to Health and Disease Washington, D.C. July 18-19, 2001 URL: <a href="http://www.genome.gov/10001665">http://www.genome.gov/10001665</a> Thanks for your help! Karin Remington	Permissions
to whom this may concern, I am a practicing artist working on a historic piece of art. I would like to include a portion of the human genome to symbolized the time period in which the piece was created. Can you direct me toward this information? Thank you Gordon Allan	Permissions
Hello First of all I would like to congratulate you because your website and your talking glossary. I'm interested in using some of that graphics (the list is below) for doing a little explanation prospect about DNA. I'd like to know if I can feel free to use it(including the author's name) or if you request doing something to me in order to use that graphics. Graphic's list: DNA replication Exon Thanks. Best regards. Eva	Permissions
Hi! I have found a schematic drawing of DNA on a homepage: <a href="http://neanderthal-modern.com">neanderthal-modern.com</a> . It is published with your permission and now I wonder if I can use the same figure in a literature project I'm working with. I won't use it without your permission. Is there someone to ask? Best regards Sara Brolin, Uppsala, Sweden	Permissions
We were admiring the diagram of the chromosome etc at <a href="http://www.nhgri.nih.gov/DIR/VIP/Glossary/Illustration/chromosome.html">http://www.nhgri.nih.gov/DIR/VIP/Glossary/Illustration/chromosome.html</a> and was wondering if one of our colleagues could use it in a talk she was doing (credited to you, of course). However, we wanted to put the talk up on our website for a couple of months afterwards, including illustrations. Is any of this remotely possible or are there copyright issues/payments to resolve? Yours sincerely, Jane Seymour Food Standards Agency	Permissions
hi, i'm writing to ask the permission to use a picture from your website on the website my biology12 class is producing as a school project. The picture is a DNA double helix. i was unable to locate the picture on your site but i had previously located it at this address, <a href="http://www.neanderthal-modern.com/images/dna.gif">http://www.neanderthal-modern.com/images/dna.gif</a> we were instructed to ask for your permission for the use of this image. thank you very much for you time sincerely Justin Rolls (millwood high school, Sackville NS Canada)	Permissions
Dear Sir, I am writing for permission to use a drawing of DNA that came originally from your website and now appears on <a href="http://whyfiles.org/126dna_forensic/3.html">http://whyfiles.org/126dna_forensic/3.html</a> I wish to use the image on the website that I am constructing to support my course on the Law of Evidence at the University of East Anglia, Norwich, UK. If permission is granted, please indicate how you want your copyright acknowledged. Yours sincerely, Rosemary Pattenden School of Law UEA Norwich NR4 7TJ <a href="http://www.uea.ac.uk/law">http://www.uea.ac.uk/law</a>	Permissions
Hello, I am producing an information kit about chromosomes for high school students in Perth, Western Australia. I would like to have permission to use a diagram on your website entitled "Chromosome". I would include a reference to the National Genome Research Institute. Although the information kit I am producing is for educational purposes, there is a fee attached to cover costs. Could you please advise me if it is possible to use your diagram and if so, what is the correct way to reference it? Yours sincerely, Britt Granath Project Officer Department of Health Western Australia	Permissions



I am a nursing educator at a BSN program(Belmont University) in Nashville TN. I am currently working on a continuing education course for Western Schools Publishing. I would like to obtain diagrams for publication of Autosomal Recessive Transmission, Autosomal Dominant transmissoin and X Linked Inheritance. Could you please direct me to the correct person(s) first of all for permission to publish and where I might obtain these 3 diagrams. Thank you for your time, I look forward to hearing from you.	Permissions and access
Dear Sir or Madam, I am writing to see if your organization would consider linking to ours as resource for information on stem cell research. Stem cell therapy can be defined as a part of a group of new techniques, or technologies that rely on replacing diseased or dysfunctional cells with healthy, functioning ones. These new techniques are being applied experimentally to a wide range of human disorders, including many types of cancer, neurological diseases such as Parkinson's disease and ALS (Lou Gehrig's disease), spinal cord injuries, and diabetes. It is the goal of the Stem Cell Research Foundation to help realize these hopes by supporting innovative basic and clinical research in the emerging and critical area of stem cell therapy. The link to our home page is <a href="http://www.stemcellresearchfoundation.org">http://www.stemcellresearchfoundation.org</a> . If you have any questions, please do not hesitate to contact me by email at <a href="mailto:PublicEd@stemcellresearchfoundation.org">PublicEd@stemcellresearchfoundation.org</a> or by calling 1-877-437-2423. I look forward to hearing back from you. Best regards, Ed Berger Manager of Website Operations	Please link to us
Would you be interested in providing a link to the University of Utah Genetic Science Learning Center website at <a href="http://gslc.genetics.utah.edu">http://gslc.genetics.utah.edu</a> on your page of Online Genetics Resources for Educators and Students ( <a href="http://www.genome.gov/10000464">http://www.genome.gov/10000464</a> )? The Learning Center's mission is to help people understand how genetics affects their lives and society. In collaboration with secondary teachers, we develop animated, interactive online and classroom-based materials focusing on genetics, biotechnology and bioethics. Modules on our website include "The Basics and Beyond", "Genetic Disorder Corner", "Cloning in Focus" and "Stem Cells in the Spotlight". We hope you will take a look at our materials and consider adding a link to them on your website. Thank you. Sincerely, Louisa A. Stark, Ph.D. Co-Director University of Utah Genetic Science Learning Center	Please link to us
Now THAT's a hot web page!!!!	Praise
very cool changes, especially clicking on the floors of the house!!!! Great job.	Praise
Dear Sir/Madam, Our Unit would like to purchase a CD, "Training in survival rodent Surgery, Office of Animal Care and Use" from your Institute. I should be grateful if you could send a pro-forma invoice to me by fax (no.: 852-2872-7598) including price, shipping and handling charges to Hong Kong. Our address is as follows: Laboratory Animal Unit The University of Hong Kong 10A Sassoon Road Hong Kong (Tel: 852-2816-8515) (Fax: 852-2872-7598) Thank you for your kind assistance in this matter. Best wishes, Shirley Yeung (Miss) Laboratory Animal Unit The University of Hong Kong	Seeking CD
Hi, I hope you can help me. I subscribe to 'Nature - International Weekly Journal of Science' and sometime ago a CD ROM came with the magazine. The CD ROM was titled 'The Human Genome Project' and is excellent. I am Head of Biology in a school in Suffolk, England and used the CD ROM as a teaching resource. Unfortunately, the CD ROM is broken. A pupil in one of my classes stood on it. I would like another copy. Do you have any copies available? If not, do you know where I could find another copy? Best wishes, Andrew Birbeck (birbs@yahoo.com)	Seeking cd
Where can i possibly avail of the Human Genome Project CD ROM. My girlfriend who is a teacher in Biology would like to have a copy. Thank you	Seeking cd
Dear Gentleman. my name is Carlos Francisco Ortiz Carvajal, student of right (laws), assistant of chair and academic investigator, in the faculty of juridicas sciences of the University of Atacama, Chile. I go to you to consult if it is distributed, by yours society, a remote course or a course on line on the human genome, in which outside possible to participate. Of not existing a course in those conditions, I consult if it is possible could attend and orient on studies and independent investigations to me on the human genome, and, ademas, allows me to put under their consideration and revision my independent advances and investigations on the human genome. Specially in the tematica "the right before the Human Genome". Waiting for his favorable consideration and attendance, it salutes to him brotherly in the knowledge, Carlos Ortiz C. Mailing dress: Universidad de Atacama Facultad de Ciencias Jurídicas Sr. Carlos Francisco Ortiz Carvajal Av Copayapu N° 485 Copiapó. III, Región CHILE	Seeking course
I am a Special Education Teacher at McGavock High School in Nashville, TN. I teach Biology and my students a able to take the standardized test for graduation. I am looking for resources in all forms and a Human Genome Project educational kit would be very beneficial for me and my kids. I this is possible please mail to Kevin Koster 3150 McGavock Pike Nashville, TN 37214 Thank you for your assistance Kevin	Seeking educational materials
Gentlemen: I teach biology at Bernalillo High School. Please send me 60 copies of the booklet, "Genetics, the future of Medicine". My address folows: Charles McClenahan Bernalillo High School 250 Isidro Sanchez Rd. Bernalillo, NM 87004 Thank you, Charles R. McClenahan, Ph.D.	Seeking posters/brochures

I'm currently taking a class at the university. We are doing a videoconfering with some scientists in NASA at Houston. Our main topic is genetics. I came across the timeline - Landmarks in Genetics and Genomics. This is wonderful! It covers the topics we are discussing. I was wondering if I can have a larger copy or poster of the timeline. I tried to enlarge it, but wasn't successful. Also the larger I made it, the blurrier it got. If you can spare some extra, we are 25 in the class. My address is 5302 Freedom Ave. Edinburg, TX 78539. Thanks	Seeking posters/brochures
I am wondering if there are any materials, like posters or brochures, that are specific to DNA Day on April 25, 2003? I am new this year in the position of Genetics Program Director at the Indiana State Department of Health and it seems to me that DNA Day would be a great means of public education and awareness of genetics! Any help or suggestions you can provide to "advertise" DNA day is greatly appreciated. Thank you!	Seeking posters/brochures
My students and I will be attending the Genome Celebration April 14-15. Would it be possible to receive 4 posters that NHGRI made have already made to advertise the event? We'd like to collect autographs on them. If you have a PDF or PowerPoint file of the poster, I'd be happy to print copies here! It looks like a wonderful symposium.	Seeking posters/brochures
Dear Sir/Madam, I am a student of MSc. Structural biology in South Africa and I have this urgent need to decorate our new lab with posters of structures that have featured as PDB molecules of the month or now especially those related to the Human genome .I am unable to find posters of that nature. May be you can help me in my quest.Free posters or any that we would have to pay for will be welcome. My postal address is: Department of Biotechnology, Structural Biology Group, University of the Western Cape, Private bag X17, 7535, Bellville South Africa. Kind regards, Ndoria Thuku	Seeking posters/brochures
When and where could I borrow the April 14th conference videos? I want to see 50th anniversary celebration of deciphering the genetic code and the announcement of the completion of the HGP. Many thanks.	Seeking video
Hi ! Recently I saw the video "Deciphering Nature's Alphabet". I was told that it was produced ny NHGRI. Can you, please, advise me where I can buy this video ? Thank you very much.	Seeking video
Dear Sir/Madam I have some questions which it is very important for me to get an exact answer for it. I will be so grateful if you answer my question. I want to marry with one of my cousins( my mother's sister's daughter ), I want to see if there might happen any possible genetic problems for our children (like diseases,...) , I mean is the possibility more than other marriages. Is there any way like blood tests,... to inform us ( before marriage ) that there will happen problems for our children or we won't have any problem. Please tell me your idea about these kinds of family marriages. I am really worried; please help me in this situation. If you need any more details for my case to answer my questions exactly, please tell me. Thank you very much Your sincerely Ali Fotouhi	Specific condition
could it be possible if the ageing gene can be removed,so that person could live longer?	Specific condition
Since the recent Supreme Court ruling striking down sodomy laws, there has been a great deal of debate regarding the nature of homosexuality - wether it is an individual choice or if there may be genetic influences within individuals that predispose them to momosexuality. Is anybody researching the possible links of genetics to human sexuality?	Specific condition
I am frankly amazed that you don't have more on alzheimer's disease and other similar degenerative dementias. The public health implications are huge. Here in Wisconsin, the "joke" is that we should not drive in certain counties after dark due to the elderly demented population. dr. d. neunaber	Specific condition
Whether, reconstruction of the retina, optic nerve and visual cortex cell growth can be regenerated via stem cell infusion? The answer to the above question is contingent upon the genome identification with respect to the retina, it would consist of the schematic representation of the optic part of the retina: 1.Internal limiting membrane; 2.Nerve fiber layer; 3.Ganglion cell layer; 4.Inner plexiform layer; 5.Inner nuclear layer; 6.Outer plexiform layer; 7.Outer nuclear layer; 8.External limiting membrane; 9.Layer of rods and cones. The stem cells would regenerate retinal cell growth along the biochemical pathway up to the visual cortex. Thus enabling vision to the impaired. Would it be possible for myself to undergo testing for the above representations? Please advise. Thank You, Al Navarro (928) 759-7180	Specific condition
Will it be possible to clone cells and have them injected into a damaged organ for regeneration of that organ?	Specific condition
I'm having a difficult time trying to find information on Greig cephalopolysyndactyly syndrome. I have looked through your website and through specific areas relating to it, and have come up blank. Do you have any material that I could read about this syndrome? Or can you give me the title to a book involving this genetic disease? Thank you for your time. Gesseca	Specific condition

They have just taken my hormone replacement off the market, I have been on them Premarin 1.25 for the last 16 yrs, I react VERY badly to synthetic hormones, IS there any other hormone replacement ,that is based on natural products that will help me, I never have had a bad reaction to Premarin 1.25, Why did they take it of the market, the lower dose Premarin makes me sick, and my girlfriend died taking them , but, the 1.25 had NEVER given me a bad reaction, Please help me, as I want to find a good replacement ,that won't make me sicker. Thank - you for your time !! Virginia Leigh	Specific condition
Are you going to do any genetic research or what chromosome the condition, Tourettes Syndrome is on. Or do you have an idea already what chromosome it is on, if so which one? Thank you for your help.	Specific condition
My name is Heidi Droegemueller. I live in Mesa, Arizona. Two years ago, after the birth of my first child, I learned that I have a balanced chromosome translocation of the short arm of my six and X chromosomes. I passed this translocaiton on to my son, although it is unbalanced. I gave my son my normal x chromosome, and my abnormal six chromosome. My son has several congenital birth defects, including an atrial septal defect (repaired surgically 11/02), stage one hypospadias, infantial scoliosis, and hypotonia. He is developmentally delayed as well. His geneticist, Dr. Kirk Alec from University of Arizona, has told us repeatedly that we will never know specifically what genes my son is missing from his sixth chromosome or know what proteins his body lacks. From the numerous reports I have heard on NPR and articles I have read in several publications, it seems likely to me that we should be able to obtain that information as a result of your research. Would you be able to assist me in this obtaining this information? Are there any ongoing research studies we could participate in? I look forward to your response. Thank you. Heidi A. Droegemueller 4725 E. Brown Rd., Unit 57 Mesa, AZ 85205 (480) 325-0954 (Home) (480) 627-5372 (Work) hdroeg@franklloydwright.org droegenote@aol.com	Specific condition
hi... my name is cherwin jay mcmeans, i was born the in the philippines and so was my dad now he's living with my grandfather in san antonio texas. i would like to ask you a question regarding DNA. i would really appreciate it if you could answer my question, well here it goes... you see my dad was a premarital child, he was born after WW2 my grandfather then was shipped to japan for military duties. well they managed to track each other and now their together, recently they had to go through a DNA test a requirement set by the INS. turns out my grandfather isnt really my grandfather, and everything that we believed in isnt true. would you suggest that they go through another test for a second opinion or chances are the results will be the same. and is DNA testing really that accurate to trace your lineage? thank you	Specific condition
dear Dr; I would like to receive information about the relationship between aberrant or anomalous bile duct and hereditary bronchial asthma. thank you Dr Alberto Adolfo Dujovne Trosman MD Obispo Moscoso y peralta 2956 CP 5009 Córdoba Argentina Phone: +543514812928 Fax: +543514238153	Specific condition
I am looking at your website wherein you give information on rare disorders, diseases, but nowhere did I find info on chromosomal disorders. I suggest you provide such information and cite our website <a href="http://www.wiley.com/borgaonkar">www.wiley.com/borgaonkar</a> which is publicly accessible.	Specific condition
I would like to find out more about inverted centromere of the chromosome "y".My son was noted to have the anomaly during a routine amnio done for maternal age.	Specific condition
I have been diagnosed with the beta thalassemia trait and constantly test as being anemic when my blood work is done. My question is this: during a certain time in my religion we are asked to fast from food and drink between the hours of sunrise and sunset. This is approximately 12 hours. Is it okay for me to go without food that long?	Specific conditoin
Dear Sir or Madam Illustration of a chromosome tranlocation. On your website you show a very clear reciprocal/balanced translocation between chromosome 4 and 20. I would like to know whether this translocation is observed in any type of tumour or whether it is associated with any genetic abnormality. Thank you very much. Look forward to hearing from you soon.	Specific gene
What can you tell me about karyotype 45x, 47xxx?	Specific gene
My daughter has this genetic abnormality and I was wondering if you might have any information on it?!? 46,xx,add (9) (q34.1) .ish der (9) t (9;13)(q34.1;q32) (wcp13+,9qtel-,13qtel+) Sincerely, Cynthia Toomey	Specific gene
Hello- I am trying to access the protien data bank to get molecular data that I am using to create art work with. I am particulairly interested in getting the structure for DNA in the "vrml" file fomat. I also want to download molecules. Please let me know the most direct way to access these via the internet through a specific address, Thank you for your time. Best, Mara Haseltine	Webmaster
I get an error when I try to listen to your audio definitions. Below is the error that I get. Are you still providing this service? pnm://multimedia.nhgri.nih.gov/DIR/LGDR/Audio/definition_of_dna_252.rmd	webmaster

We're building a website to cover the work being carried out by a new genetics research and education consortium in London, UK. I'd like to link to your genetics glossary as it's the best one I've found on the web. I wondered if: - there are any changes planned to the url etc - is there a url I should use for the link that is more stable than the url I see when I visit the glossary home page? Many thanks Amy	Webmaster
I have read a number of scientific papers that cite to a cretain site, <a href="http://www.nhgri.nih.gov/Intramural_research/Lab_transfer/Bic/">http://www.nhgri.nih.gov/Intramural_research/Lab_transfer/Bic/</a> regarding a list of known BRCA1 and 2 mutations. I cannot seem to locate either the website or the underlying information from your site. How can I access this information?	Webmaster
Your site is wonderful, and your genetics glossary the best I have seen. But it is a tragedy that you make your audio descriptions dependent on Real Player, which is not only grossly commercial, offensive in its obnoxious use of ubiquitous adds, but also doesn't work on many systems such as my network. Why not use Windows Media Player, which is already bundled with windows, which is run by 90% of computers, or QuycikTime, or one of the others. By using .RAM format you insure only Real Player can read it, and many of us have been forced to uninstall Real One for various reasons. I am really disappointed that you would back an exclusive commercial product like this. Media player is truly free to all windows users. Real One only has a minimal program which is free, and it has the grave cost that it will nag yiou to death, and drive you crazy trying to download additional functions from its web site which are almost impossible to access or install. Real One is a fantastic time-waster.	Webmaster
Is the NHGRI website and its contents public domain? I work for a non-profit organization that mirrors sites for developing countries on their intranet sites. Specific parts of the NHGRI site would be helpful to those university students learning medicine. Thanks!	Webmaster
Are the zip codes correct? 20850 is listed for almost all, even the folks in Baltimore. f	Webmaster
My name is Jennifer Turner. I am a Teacher for AMDEC (the Avon Maitland Distance Education Centre) - an online learning initiative which offers Ontario high school credit courses through electronic distance education. I am writing to tell you that I find your site very interesting and useful, and will be providing the URL as a resource to my students. They may be accessing it for study and research purposes, beginning in September of 2003. If you would like to know more about AMDEC please visit our website at: <a href="http://www.amdec.ca">www.amdec.ca</a> . Sincerely, Jennifer Turner Teacher, HSP3M	Webmaster
I have trouble understanding the search results when I do a search within the NHGRI website. For example, when I type in the words 'NIH surplus' looking for directory, I got a listing that has nothing to do with what I had in mind. Is this a site that has only documents and the search goes strictly by wrds in the text document?	Webmaster
I am writing to encourage you to visit our website, <a href="http://www.myziva.net">www.myziva.net</a> . MyZiva.net is a completely free site for caregivers, healthcare professionals, and prospective residents and their loved ones to find, evaluate, and compare nursing homes in their local community. It is a comprehensive searchable directory of all nursing homes in the entire nation containing addresses, phone numbers, driving directions, and government data including Survey (Inspection) Reports, Quality Measure Rankings, Staffing Hours Ratios and more. We also provide members (joining is absolutely free and takes only seconds) with the ability to save selected facilities on a personalized homepage, as well as a unique feature enabling users to compare nursing homes side-by-side. Thank you for your time and consideration. Very Truly Yours, ron lebow	Website advert

<p>To Whom It May Concern: My name is Cheryl Hake and I would like to ask you for some help. I have done all I can do by myself and have no choice but to find someone else who cares as much about this cause as I do. My best friend, Bea Frantz, is a very sick lady. I will explain her condition as simply as I can because she has very complicated disease. Bea is suffering from a disease called Mannose Binding Lectin Defect. This can only occur to people with a mutated gene in the liver. This mutation is a defect that occurs during gestation. When bacteria enters a healthy person's body, the liver produces a binding protein that attaches itself to the bacteria. That way the neutrophils, the bodys army of germ fighters, can stick to the bacteria and kill it. In Bea's case the white blood cells, (neutrophyls), can't attach themselves. It is life threatening for her to get a cold or the flu, but the major battle she is facing is staph infections. She suffers from MSRA which is known as antibiotic resistant staph infection. This form of staph infection is the most deadly and serious of all forms of staph infections. These infections begin in the bone and work their way to the surface of her skin. She is in constant severe pain. She has to be hospitalized often, however, there is little or nothing that can be done for her, even there. Her hospital stays can last as long as three months at a time where she is in isolation. She is not able to leave her private room and those who visit must be gowned for Beas protection from outside germs and illnesses that could be brought in to her. She has been pumped with so many antibiotics for so many years that she has become either allergic or immune to them. She now is down to the last antibiotic mixture that is available for her. One of the problems we are facing is that not much is known about this condition. There are less than 300 people in the world who have this disease. Consequently it is not high on the research list to find a treatment or cure. Bea has been to the Mayo Clinic several times with no permanent solution. There may be one more hope. Bea had a doctor, who worked at the University of Davis Hospital, in Sacramento, California, who was in touch with a hospital in Belgium that had developed treatment that would put this disease into remission, though it was still in clinical trial. He was hopeful in getting Bea involved in the clinical trial with this medication. Unfortunately that doctor is no longer working there and did not inform Bea how to get in touch with the researcher in Belgium.. He told Bea he did go to Belgium and tried to bring the medication back for her but was not allowed through customs with it. Our delemma is that we have no idea what the name of the hospital he was in contact with is. All we have is an e-mail address and we have e-mailed them many times but get no reply. Finding a cure or treatment is not the only thing Bea has to worry about. Her medical bills are astronomical! We have started a fund account called Cash For a Cure and we have fund raisers to help defer some of her medical costs and we want to build up a reserve for when we can find out when and where, in Belgium, this drug is available for human testing. Bea's goal is to establish "The Beatrice Foundation" where others suffering from this condition can find answers to questions and where Bea can give them an account of what has been done medically for her as well as support to those who are in need of someone to care and undertand what they are going through. She has basically had to go through this alone not knowing what to expect. Bea has already decided to donate her body to science for research so that more can be known about Mannose Binding Lectin Defect. Let me tell you a little bit about Bea. She is only 40 years old. She is one of the most unselfish people I have ever met. One day we were going to town and I could tell she was uncomfortable. I asked her if we should go back to her house and she said, " I am in pain all of the time and I could sit at home feeling sorry for myself but there are too many places to go and too many lives to touch." And touch lives she does! Bea is very strong in her faith in God. Her family is also very supportive. If not for those two things, she would have been dead long ago. Pain has a way of wearing a person down and God, family and friends have helped her in her fight. I feel, not only would you be helping her by doing a show about her but perhaps there is someone else out there fighting the same battle who doesn't know what to do either and might see the show. You would be able to help put others needing support in contact with her and her with them as well. the one thing Bea does not want is for anyone to feel alone through this illness and to know that she will be there for them and understands the difficulties they face. Please help us! Thank you for your quick response to this plea and thank you for taking the time to hear what I have to say. Yours Very Truly, Cheryl Hake</p>	Weird
<p>I know a gentleman who is currently in San Quentin State Prison. He has a degree already and wants to get a degree in Associates Arts Criminal Justice. Can you please mail him some information on correspondence courses that he can take. David M Franklin San Quentin State Prison San Quentin, CA 94974 T89860</p>	Weird
<p>hello. The domain name: InsideYourGenes.com is for sale. It should be noted that 90% of the proceeds will be directed to biological research; namely molecular level vibration interaction and its potential applications within medicine. Any offer should be sent to mook44@tiscali.co.uk. Thanx for your time.</p>	Weird
<p>It is very interesting reading regarding Progeria and some of the recent findings in recent times. My son Christoper Balnaves was a sufferer of Progeria for nearly 21 years. My brother Robert Balnaves suffered from Muscular Dystrophy for 33 years. Is this a coincidence or more closely linked genetically. Chris Balnaves recently passed away, certainly the eldest in Australia with Progeria and perhaps the oldest in the world. If ever I can be of assistance of any kind with historical data please let me know. Regards Murray Balnaves</p>	Weird

<p>Hello, i wondered if you could give me any information on what i have questions and ideas about or if you could give me the contact information for somebody who may be able to help me. I have been studying genetics and genetic engineering for a few years at A-level so i do not fully understand everything i need and my suggestion may be wrong because of my limited understanding. i have recently heard about a gene called delta-32 that arose in abundance around the time of the black death in europe and provided the people that had the homozygous form of the gene with almost complete protection from the plague and from HIV/AIDS which are coronavirus'. Could a coronavirus be used like adenovirus' in gene therapy with the delta-32 gene inserted into its own DNA so that it targets white blood cells which are affected by SARS to provide immunity to the SARS virus - or other coronavirus'? i realise that there are other ways that coronavirus' can infect host cells, mutant forms of AIDS virus can attach to the CXCR4 receptor. I had this idea and i know it may be flawed but i would appreciate any feedback/information you could give me about my idea or if you could give me the contact information for somebody who could help me or even be interested in my idea. Many Thanks, Louise Dunnett</p>	Weird
<p>Hi this is why i am E-mail you because i need some info about your Envirment. I was woundering if you can send my some stuff that you go at your envirment. How oftin do you and your co-workers meat a week.This is for wellens</p>	Weird
<p>Tromso, Norway, March 03, 2003 Dear Health Scientist A MUST READ BOOK You should absolutely read the book Genetic Catastrophe! Sneaking Doomsday? written by the discoverer of the GC. You may browse the whole text of the book for free at iUniverse.com (the bookstore there). This operation is simple and fast. Or you may buy the book from main internet bookstores, or order it via ordinary bookstores. The word "doomsday" in the title of the book has nothing to do with religion, and the book does not discuss gene technology, human breeding, and other politically incorrect subjects. So what does it discuss? It discusses the high and increasing prevalence and high and increasing incidence of genetic damage/genetic disorders/genetic diseases all over the world, and logically concludes that we have a genetic catastrophe. The book also shows how the scientific community is misunderstanding, defining away and perhaps even covering up the GC. You simply have to read this book. So far you have no alternative book to read if you want to know and understand the genetic catastrophe. Be among the first to know and understand. Most sincerely, Nils K. Oeijord</p>	Weird
<p>The human Genome Project: Is it good or bad, one main reason it's bad is because when you map out all of our 46 chromosomes, people could know if they have a disease, so meaning if companies get a hold of it, they will make it mandatory to take a blood test, and maybe refuse to employ people who carrie a specific disease, that won't hurt anybody else. I really don't think the Human Genome Project is such a good idea, because our world could be turned like in the movie "Gattaca" and i'm bearly 14 and that could happend to me! If you can't stop it, at least don't get the companies hold of that information Thank you for your time from:bryan88now@aol.com</p>	Weird
<p>To the Task Force on Genetic Testing, I am a PhD student from de University of São Paulo (USP), in Brazil, and am doing a research about the introduction of genetic tests into medical practice. Since there is no information about how many laboratories are offering services in this field, type of institution offering genetic services, which tests are being done, which difficulties are they struggling with and how are the tests being validated, I became interested in finding these answers by doing a qualitative exploratory study about it. I have already done about 30 interviews to specialists and mapped all the laboratories that offer genetic services. Now, I am elaborating the questionnaire to characterize them and see how the tests are being employed, but I do not have any model of questionnaire that I could applicate. I really got very excited when I read the articles published, about the efforts on quality assessment of molecular diagnosis on clinical laboratories and its characterization. And I was hoping if it would be possible to see the questionnaires developed and utilized on your research, as a reference model for the development of mine, on the Brazilian context. Thankfully, Cora P. Hors, MSc</p>	Weird
<p>DEAR SIR, I AM TENNETI.VIJAY KUMAR WOORKING AS A MIDDLE LEVEL OFFICER IN A STEEL COMPANY. I HAVE DEVELOPED AN INTERESTING MATHEMATICAL THESIS KNOWN AS "TENNET'S THOERY OF EXISTENCY".WHICH CAN EXPLAIN MATHEMATICAL MODEL OF CHROMOSOME SEQUENCES THAT MAY BE USEFUL FOR YOUR RESEARCH. THIS MATHMATICAL MODEL IS BASED ON VARIOUS GENES TOPICS PUBLISHED IN VARIOUS MAGAZINES. IT IS MY HARD WORK SINCE 15YEARS WHICH IS NOT HAVING ANY USE IN MY PROFESSIONAL LIFE .SO PLEASE GO THROUGH THIS PAPER. I AM INTERESTED TO SUBMIT MY HARDWORK TO YOUR ORGANIZATION. THANKING YOU, WAITING FOR YOUR REPLY. TENNETI.VIJAY KUMAR</p>	Weird
<p>read www.paradiserevelationsdiet.com notes on way to you at bethesda for max muencke and all others this is health;this Fefrunark items 123, 127 130, 133;or holocausts soon if not told to all</p>	Weird
<p>sickle cell anemia is cured by technology that supports the brain stem and graphically supports blood flow to the brain.</p>	Weird
<p>Concerningdefiniton of an exon. The definition is wrong:"The region of a gene that contains the code for producing the gene's protein. Each exon codes for a specific portion of the complete protein" An exon is the region of the gene that is found in the mature mRNA (as mRNA). These sequences do not always contain a coding sequence. may exons are NOT translated.</p>	Weird

## Interview notes for A01

Thu 10/30/03

### Take-away:

- For people look for info on a specific disease or condition – give better direction if genome isn't covering that particular one rather than leave the visitor to sort the list other places they might look.
- Provide means for ordering hard copy of ed kit, likewise the CD-ROM (or else at least explain that it isn't available any more)
- Consider expanding the Ed area to help students with homework better – perhaps by looking at the list of requests that come to the web-master to see what kinds of things students are asked to look up.
- Careers and Training isn't student friendly – terminology seems more “adult career” oriented
- Programs for Minority and Underrepresented students needs to be more prominent

Answers webmaster queries via an on-line form (“email to webmaster”) and via phone. He uses genome.gov and other nih online resources to locate the requested material. Generally he gives the person a deep-link to the requested material. In some cases it is information that is buried on the site, occasionally it is easily obtainable and the requestor was simply didn't look too hard. E.g. asking how to locate Francis Collins.

It takes two clicks to find the “email” form. One on Contact and another on the Questions and Feedback Page link. The Questions and Feedback page also gives a phone number.

Handles 7-8 phone calls and 9-10 emails per day from media and general public. Quite familiar with the site since he mines it looking for the info that has been requested through email and phone calls.

Rough categories of primary content people are looking for:

Info on specific diseases or conditions

- asking for ones that are both on genome and some that aren't
- note: can't put them all, there are over 6000
- the site lists other resources, places people can call
- this audience is sometimes emotionally vulnerable, have often been searching on the web and getting frustrated. Finally arrive at genome hoping to find the info they want
- Oftens sends them to the Genetic and Rare Diseases Info Center
- Sometimes sends them to specific research projects if that project is working on the disorder being sought

#### Grant info – hard to look up

- have to go through CRISP db on NIH - which is difficult to use at best (search options not easy to understand), and is not genome specific, covers all of NIH
- There is a NHGRI db of active grants on genome.gov which was discovered during the interview
- Finding funding opps is tedious, requires many clicks and reading through dense information

#### Ed tools for teachers and students

- Ed section has sooooo much on it, sometimes makes it hard for visitors to locate information
- Ed kit released in 2001 w/CDROM, video, and articles. Added more curriculum guides since then.
- Some schools don't have the technology to be able to download and use some of the pieces like the video. Teachers looking to order hardcopy of the Ed kit.
- There isn't a way to order a hardcopy of the materials from the Ed kit.
- Students
- Don't know where to start,
- Some just email genome right away, some look first
- Most have a topic in mind, something they need to learn about to complete a homework. E.g. genetic testing. But there aren't always such specific materials in the Ed area even they are available elsewhere on the site. *(The only "by topic" section in the Ed area is sort of off of the Fact Sheets link. And the possibly useful brochure, "Genetics: The Future of Medicine, details the goals of the HGP and explains its potential consequences. It includes illustrated explanations of basic genetic terms and concepts." is on the HGP page.*

#### Reporters

- this population is more likely to call him on a regular basis because they know he can save them time by taking directly to the information they are after. (often on deadlines)
- Often looking for updates on on-going scientific projects. What progress has been made, how much has been spent. What has been awarded. Which companies have been funded and for how much
- This population includes major newspapers (Washpost, NYT, etc.) as well as trade magazines, and "genome technology".

#### Investigators, scientists, reporters, and college students

- tend to be looking for info on certain projects and initiatives
- Sends them to the projects page (which is perfect, don't change it). The problem is getting people to the projects page (10001694 *(it's not labeled as such, it's labeled as "genomic research")*)

#### Search engine

- bring up links quickly (fast response time)



- saves him clicking thru links to get to pages
- always get stupid hits and irrelevant pages E.g. “genetic testing” is all over the place. But that’s not a problem for him.

#### Policy and Ethics

- before redesign used to get questions about state legislation

#### Careers and Training

- Recruits students at exhibits. Tries to send them specific links because that area is difficult to navigate accurately. (*too many links look the same?*)
- Professional Training and Career Development link on C&T Tier-2 page looks like header and so people don’t click on it
- Interviewer thinks that Professional Training and Career Development doesn’t have good information scent for a student
- Big effort to recruit minority and under-represented students – and that link is on the right – not prominent enough

## Interview notes for A02

Thu 11/6/03

### Take-away:

Uses the website for her own work. Both to advertise special events she has organized and to look up information she needs.

Part of her job is organizing special projects events, e.g., 50-year celebration. Used genome.gov to post info about it as well as advertise it. Big help to be able to refer people to the web for info about the event. Sometimes refers people to the Rare Diseases page.

Also uses the website to keep herself up-to-date with happenings at genome. E.g, checks out the news links on the HP (doesn't usually go to Newsroom). And checks out the calendar to see what events are happening.

Works for Deputy Director, doing special events. For smaller events not open to the general public, doesn't use the site to advertise. Instead sends attendees straight to contractor site that handles registrations, travel, hotel, reimbursement, etc.

Big public event being organized for spring, "Chemical Genomic something". This will be public. She expects to post a link on the site that will take potential attendees to the contractor sub-site for registration, etc.

"web-team quite responsive"

"hearing good things about the re-design"

Uses genome.gov to

- find DIR researchers (look up contact info and locate bio info) – doesn't look up DER researchers very often because already knows what is happening there since they are in the same building.
- read new press releases (gets these from HP, not newsroom)
- Research – wasn't sure there was DER info there. I asked her to look and tell what she thought and after a moment she concluded that the left column had DER info. *But of course she knows those projects and outsiders won't...*
- Health – only uses to refer people to the rare diseases page
- Policy and Ethics – has look at a few times, mostly to look up state legislation
- Ed – only use of this page is when organizing an event that is also putting out an educational component.
- Career & Training – never uses
- Grants – never uses
- Newsroom – gets news from HP

- About – been there. There's content on long-range planning that is hers – she's also the contact person for it. Pulls bio on Director or info on advisors on the council memberlist.
- Staff Search – doesn't list her for "Vasquez", but does for her maiden name. Doesn't give office number or email

#### Intranet

- uses some, likes new HP for it
- most of the info she needs is on genome.gov
- not yey using it regularly

#### DIR internal site

- sometimes she needs info that is on there but it is password protected.
- E.g., Retreat information from this past year

## Interview notes for A03

Thu 11/6/03

### Take-away:

Little use of website. Occasionally uses it to look up contact info (phone #) of another DIR faculty member. Primary use is for retrieving IRB forms.

- Would like IRB Calendar to be available

Health – wrote some of the content, never used

Policy – never used

Ed – contributed some content, never used

Grants – never used

Calendar of Events

- would like to have DIR Seminar Series linked from there since it is open to everyone
- Wonders why DIR Seminar Series lecture that was at 11:00 today (11/6) wasn't highlighted on HP but the Brown Bag seminar was (which is mostly for students)
- Odd that it has material dating back to 1997

Externals

Fellow scientists he works with don't need to use the site.

Students seeking positions will sometimes find his info and contact him directly -- telling him about their submitted application.

- gets "blanket" emails, often sent to everyone in DIR
- when has a post-doc position open will send notice to fellow faculty at universities with announcement and a link to his page (which describes his research).
- Also directs them to ??? NIH

Small gripes:

- Calendar of Events on HP doesn't look like a link and also has no rollover
- HP not stretchy
- Not all items have rollover
- On HP at top, would like to be able to expand/collapse shortcuts to see more/less info (minor minor thought)
-

## Interview notes for A04

Wed 11/12/03

### Take-away:

Search results not useful for finding information such as an investigator or a specific disease or condition. Does well for a few, but not many

Works with people making inquiries about jobs. Many job postings are on Inside NHGRI. People email her, she sends standard response that gives deep link to training ([www.training.nih.gov](http://www.training.nih.gov)). Her office tracks post-docs while they are here then helps them get to conferences and look for jobs (DB on InsideNHGRI)

Uses Intramural Training Office page a lot  
Does lots of minority recruitment from conferences

Her distinction between InsideNHGRI and genome.gov is a bit fuzzy, partly because they are interlinked. Spent the first part of the interview talking about a difficulty with InsideNHGRI. (Dr. McBride couldn't find ZOE's and no response from help desk – if help desk can't respond because someone is out it is important to let people know that)

Problem: InsideNHGRI feedback link goes to the form on genome.gov

Search doesn't help find people well:

E.g., someone on outside may have been told to contact a “senior investigator”  
Searching for “senior investigator” doesn't give good results. Other examples:

- “researchers”
- “investigators”
- a specific person
- a specific conditions
  - o Should give general info, researchers working on it, open protocols

No info on genome.gov on how to give \$\$\$

Health – never uses

P&E – rarely

Grants – no b/c she is DIR

Ed. Rsrcs – may direct teachers calling in there

Newsroom – never looks

## Interview notes for A05

Wed 11/12/03

### Take-away:

Uses it to see what else is going on at NHGRI – to see official public disclosures about projects he's been hearing about internally

Portal to Research pages for him and the Genetic Vars page in particular since that's where he works.

Check his canned emails to see if those are resources that should go on genome.gov

Ask web team about the Research Resources page that used to be on the old site

New site is fine, now that he's gotten used to it.

### Health

Rately uses

Policy – sometimes looks up press releases, but generally hears about anything in that section before it gets there, before it is public, from Francis

About – never uses

News room – never uses.

HP – uses the news

Receives email from people who get his name from colleagues, or from Francis's office. Francis's office knows he has good canned emails that can be sent out in response to inquiries from job seekers and teachers. Those canned emails have a list of links, some of which are internal, and some of which are to other sites.

Tries to target job-seekers to appropriate labs/researchers/opportunities. Job applicants either send him resume & cover letter or tell him that their resume/cover letter is on file with NIH.

Example of resources he sends out in canned emails (note: they aren't completely canned, he tries to target the resources as best he can)

- SNP variations and genomic variations
- CDNA seqs and where to get them
- Genome comparisons against other species. E.. UCSC (univ calif santa cruz) house the 1<sup>st</sup> genome browser.

Generally things website, now that he's gotten used to it, is fine. One page that he used a lot on the old site was a Research Resources page. He's constructed his own set of bookmarks to fill the gap.

## Interview notes for A06

Wed 11/12/03

### **Take-away:**

Puts together review panels for solicited responses

--- info about review panels is out of date

? “ who is in charge of keeping the grant pages current” ?

---- RFA-HG-03-003 out of date (deadline was may 2003)

--- RFA-HG-03-004 out of date (deadline was may 2003)

“too many clicks” (to get to RFA’s) – but upon review with me concluded that in fact it was only 3 clicks (grants, funding opps, RFA’s)

Believes that potential grantees (mostly faculty) hear about newly posted RFAs thru a variety of sources.

- announce-only listserv (run by DER, subscribe option is at the bottom of 0884)
- admin staff within colleges/univ that track grant sources for faculty
- online db’s that track grant sources

Finds it hard to locate people within NHGRI – staff search only lists phone number, not position or office location

Because he is always looking for people, he would like a more prominent staff search function and he would like it to give more information.

\*\* info about Review Panels is out of date

### **External users**

He refers other reviewers to the DIR Investigators page. It’s useful that he can just send the URL and it’s taken care of.

Gets 1 or 2 phone calls per month from people asking for help (homework, about a disease, etc.) Sometimes sends them to the Talking Glossary. Doesn’t send them to the Health page because it seems too complex and he figures that people who call want to continue to communicate via the phone.

## Interview notes for A07

Tue 11/25/03

### Take-away:

Not happy with the site. But not clear that the site could work any better for her. She has disengaged from it and built her own page that has all the links she uses for her work. Some of which deep link to genome.gov pages. Essentially a personal bookmark list. Which makes sense since some of the pages she uses are several clicks deep.

### Grants

- ELSI Funding opps
- List of funded grants – goes to db
- Separate list of pubs that came out of grants
- Updates on the list of pubs lead to odd formatting changes (10001798)
  - o This page was imported from the old site or from a word doc and hence the formatting is very sensitive. A change higher on a page (something that she sent in to the assignment desk) will cause a funny formatting change further down the page

\*\*\* how to get to planning process for ELSI??? Can still get the Vision off of home page but that's not all of it

### Pages used (from bookmarks)

10001618 – Research | ELSI Research Program  
10000930 - Grants | Funding Opps  
10001796 – Research | ELSI Research Program | Grant Abstracts A-M  
10001797 - Research | ELSI Research Program | Grant Abstracts N-Z  
10000700#elsi – Research | NHGRI/HGP Reports # ELSI Prog. Reports  
10005516 - Research | NHGRI/HGP Reports # ELSI Prog Reports | ERPEG Final Report  
10002229 – Research | NHGRI/HGP Reports | 1998-2003 Five year plan | ELSI Research

\*\*\* note from me:

1998-2003 five year plan : new goals (100001475) doesn't point to ELSI Research page (10002229). But the breadcrumbs on that page (2229) claim that it comes from (1475)

Also: (Very, very similar/confusing)

- 2229 is titled Ethical, Legal and Social Implications (ELSI) Research \*\*\*\*\*
  - o 2229 is buried, hard to find
- 1618 is titled Ethical, Legal and Social Implications (ELSI) Research Program



## Interview notes for A08

Fri 11/14/03

### Take-away:

Deeply concerned about web site's ability to help DIR recruit grad students, post docs, and clinical trial participants.

Gets email (1 per week) from general public asking about genetic diseases and conditions. He understands that his name is going to come up in google searches and that he will continue to get these random requests for information. He forwards those to Dawn Hadley and Anne Smith (genetic counselors)

Gets email from potential students and post-docs. And colleagues.

Institute not doing a good job of attractiting good students. Top students have their pick of where to go and DIR would like them to come to them.

### Careers

- 10005858 is too bland. E.g. post doc in neuroscience, wants to work on stem cells. Noting on page telling postdoc where to look. Investigators, doesn't say what they do, have to visit each one individually.
- Wants those pages aimed at grad students & post-docs to be more welcoming, written in a way that will draw them in
- Wants the page to be exciting to look at, something makes them say "this is exciting stuff"

### Contact Us

- doesn't expect to find Questions and Feedback form in there. Thinks the Questions and Feedback form to be pulled to the top or split up.

### Health

- genetic disorders some are being worked at the institute, but not all "this is a weird list"
- GARD on right, but not seen

### Research

- branches need better descriptions
- Current Clinical Research at NHGRI
  - o Some goto clinicaltrials.gov
  - o Others fo to genome pages
  - o But it isn't clear from the kubjs
  - o Links use study title. The list should be alphabetical by condition/disease
  - o Not a welcoming page for potential recruits

## Interview notes for A09

Fri 11/14/03

### Take-away:

Frequent use of genome.gov herself. Sometimes the info she is looking up she has in other resources (excel, word docs) but it is faster/easier just to ping genome.gov. Uses pages in Research and Grants. She uses the information she finds in presentations, posters, & other material she is preparing. E.g. she will look up the language of a RFA in order to be sure that materials she is preparing use the same language – or – she will look up dates.

Commonly used pages:

1694 – genomic research

1691 – seqs, maps, and BAC libs

1852 – BAC lib (has most up to date info)

xxxx – genome hub

Grants – looking for

RFAs & PAs (to check language, dates, also uses as a record of what did

Newsroom – finds news releases useful, for dates, resource for language

Genome Hub (compilation of resources available on the web)

\*\*\* only available from See Also, she's not sure that people can find it easily

Note:

DIR research resources page – all internal

Online Research Resources – internal and external???? (check)

Genome Hub – collection of genomic resources, directed towards scientists

1691 – seqs, maps, BAC libs (she helped put this page together)

Concerned that important links to related pages (also in Research) are missed. E.g., Funding opps, Policy Development & Project xxx. Other similar pages (at the same level?) have one big page and don't have it split into multiple pages.

Would like icon/picture of animal on label for on animal sequences (note this will work for awhile --- until there are sequences done on to 'things' that look the same)

Health – has sent people to talking glossary and used it herself

Policy – never

Ed. Rsrcs – will use it to get to HGP page to get timelines & language – pulls info to send (occasionally) for outreach

Careers – never

About – infrequent use

Calendar of Events – uses to track “what is up”

# Interview notes for A10

Fri 11/14/03

## Take-away:

Concerned about how well specific audiences can locate pertinent content. Minority programs & training opps difficult to locate. Careers & Training needs to be more straightforward.

Charged with Education and Community involvement.

Uses site to track what is up in DIR, what work specific individuals are doing. Often visiting Research and Research Branches for this purpose.

Concerned whether info for public is accessible. E.g. Short course – summer course – is buried. So he retreats to Search. Found it eventually, but it was out of date and not easy to locate.

Interested in advertising new program for visiting faculty to spend a year. It's under the Office of Policy, Planning, and Communications.

R-nav – doesn't look at it

Primary external audiences he is concerned with:

- (A) faculty, students (undergrad, grad, med, phd)
- (B) HS (10<sup>th</sup> grade through college sophomore) – careers, exposure to genomics
- (C) Advocacy orgs and support groups for individual patients, families (works with GARD program)
- (D) Under-represented populations

P&E – doesn't use

Ed Rsrcs – has info for the HS audience (B)

C&T – has info for (A) and (D)

- get confused, thinks things in the left column all sound too similar
- Jobs@NHGRI – thinks belongs in About NHGRI

Grants – important page

Newsroom – not commonly used

About NHGRI – not used

## Interview notes for A11

Wed 11/19/03

### **Take-away:**

Need dates on RFAs and PA's.

Wants 'real' URLs

Grants section works ok

Layout of site not suited for his personal tastes. He finds the busyness to be overwhelming. But – he is able to quickly locate the few pages he does use so it isn't a bit issue for him. I.e. He can use it but he doesn't like it. If he had to find new information it would be a challenge to him. His dislike of the site would color his experiences in finding new information.

Works with investigators at the pre-application stage to guide and advise. After submission, there is no contact.

Mixed response on “does your audience understand the difference between intramural and extramural”. Sometimes said yes, sometimes said no.

Annotations on links, e.g. the annotation under Funding Opps is important. People will clue in on the RFA and Grant keywords in the annotation.

Check how effective the highlights work to bring the eye to the pdf and SCAMS links on 0951

#'s in URLs is problematic because when giving those URLs to the public – they are easy to get wrong. (yes, but so are regular URLs, especially when they are trying to be informational about all 600+ pages in genome – still, worth exploring)

What's the diff between New from NHGRI and Newsroom section on HP?

RFAs & PAs need dates on them. (0368, 0991) Check [www.becon.nih.gov](http://www.becon.nih.gov) for examples.

What about expired PA's that are still accepting?

Doesn't always look at right hand side in normal usage. But during the interview was investigating (perhaps uncharacteristically) it more closely.

See Also on 0950 should ditch the Req for RFA's link

See Also on Grants page should go to the DER training page, not to Prof training since you can't get to DER training grants from the Prof training page

## Interview notes for A12

Wed 11/19/03

### Take-away:

Responds to queries about specific conditions. Uses genome, nci, and nih to answer those questions. Mostly finds the site gives her good information to pass on.

Writes newsletters for organizations of nurses and genetic counselors. Uses genome.gov to locate materials for the newsletter

#### Newsletter

- Uses genome.gov to locate materials of interest to the readers of the newsletter.
- Uses 100001618.
- Finds and includes funding opps for nurses in the newsletter

#### Job

- Answers calls from patients looking for info on specific conditions.
- 

People ask her where the series of articles written by Collins and Guttmayer are located. She sends them the reference on genome.gov (these articles were published recently in New Eng. Journal of Med)

#### Calendar of Events

- uses to track what's happening

#### P&E

- uses it to answer questions on anti-discrimination laws at the state level

Pulls info from NCI, cancer.gov, and NIH to answer questions, isn't just using genome

#### Ed Rsrcs

- uses fact sheets, basic research science techniques b/c written for general public

#### C&T

- refers people to public policy programs so that they know what is available
- also refers people to NchPeg

#### About Us

- used when first joined NHGRI to get oriented
- the April 2003 event materials were effective!

## Interview notes for A13

Tue 11/25/03

### Take-away:

Uses site to pull material for reports etc.

### Job

- dealing with legislative affairs
- appropriations bills directing research towards particular efforts. He tracks it – making sure that the institute is focusing on what the bills said to focus on
- makes sure reporting requirements are met (?)
- puts together congressional tours, for both legislators and/or their staff
- 

### P&E

- most frequent use (?)
- authored some of it
- thinks this section doesn't work well
  - o not consistently updated (but believes this is somewhat his own fault –i.e. that he has control over it but doesn't get around to getting more updated into to the web team)
  - o too much information
- Not sure that the shortcuts on the left are used (they are!)
- Content not substantive enough. Wants it to have more in-depth content, not just a ELSI portfolio
- Doesn't receive notification of pages needing updating
- Uses the NHGRI Planning (from See Also)
- Uses Budget & Financial info (from See Also)

### About

- uses directors page for bg info & history of NHGRI to use as filler for various docs

### Newsroom

- locates press releases
- pulls info from press releases for reports
- b/c the last item listed on the left has a date of Jun 03 he thought that that was as far back as he could go (until he clicked on the Current releases at the top)

### Ed Rsrcs

- hardly even uses
- occasionally looks at Mentorship program b/c run by OD

## Research

- uses Branches
- uses Investigators
- looks up what investigators are focusing on. Emails or calls them to arrange their participation in congressional tours

HP- only some areas on the building graphic are linked – why aren't they all?

General – should be easy to find out who does what and how to reach them. The Org chart doesn't help. Staff search only works if you know the person's name.

## Interview notes for A14

Tue 11/25/03

### **Take-away:**

Health section, particularly the pages on Genetic Disorders is not up to snuff. GARD and ORD only listed on right – they need higher visibility

Audience: patients

Infrequent user

Looks for policy info, e.g. info 'bout legislation at the state level

Works with ORD (office of rare diseases)

Health / Genetic Disorders

- not clear why those diseases are listed
- List to Univ of Kansas web page is listed, but not others that are just as pertinent
- MOST – only one listed
- Genetic support groups not listed
- No link to genetic alliance
- GARD and ORD only listed on right – they need higher visibility



## Interview notes for A15

Wed 12/24/03

### Take-away:

Hardly uses the site herself but was able to run a critical eye over some of the resources in the Research area and suggest improvements

Develops scientific resources for investigators that are available off of their own server

No use of genome.gov.

Research

e.g., Info about Sequencing projects hard to find

- would try Genome Hub off of Genomic Research page, then goes to Seq, Maps, BAC, then to Sequencing progs supported by NHGRI (suspects that the list is incomplete) – each of those pages is formatted differently for no apparent reason. And the Human genome page is Very different. Thinks there are some links that should be on that page that aren't
- DIR – no explanation that DIR means internal
- Annotation on Genomic Research – misleading “at” vs “supported by”
- Went to Genome Informatics & Computational Bio, surpsed to find Funding Opps. Expected that this page would have a link to related research tools instead of brief intro and then funding opps, gGiven that this is under Research.
- Research Resources page from HP – “really weak, incomplete” “should do well, or not at all”
- Genome Hub – looks reasonable. Note: “draft of HG seq” – no longer up to date. The sequence has been completed.

Her thoughts

- Combine Res Rsrcs and Genome Hub and make it complete

Research

Need somebody with the right expertise to stay on top of the material

Also need “last updated” note on pages

Home page

- why go take people off of NHGRI site?
- Why NCBI and not Santa Cruz?

Purple and pink HGP page – branded as HGP but is really educational materials

## Interview notes for A16

Wed 12/30/03

### **Take-away:**

Two layers of concern. Constitutents – job seekers and DIR as representative for NHGRI in general

Own use:

- Investigators list as phone directory
- Checking pages w/eye for public view
- Reference materials
- Materials for public presentations

Job seekers need to know

- branches
- investigators
- job opportunities
- org of DIR

Notes: cataloging on-going research (e.g., what genes are being studied) and keep it current would be very very difficult – serious curatorship issue

Label “PT&DC” doesn’t communicate what it does very well

Wants all DIR opportunities in one place

ITO - administrative

## Interview notes for A17

Wed 1/7/04

### Take-away:

Concerned about how potential recruits view the site and how well they can find information. But is working off of her intuition as to what kind of information they would want and how they would expect to find it.

### HP

- looks for in-house events (news, calendar)
- doesn't say enough about the Institute. Text and layout doesn't grab attention. Eyes jumping all over the place
- wants about About NHGRI to be more prominent

### About NHGRI –

- left nav works, this is the kind of information she would expect to find here
- org chart (PD) out of data and some info on it, e.g., HN415, isn't useful

right nav – not used “I must have missed it”

### Search doesn't work well

- entered “cancer genetics” and genetics cancer branch doesn't come up
- 

would be useful if there could be a link between genome.gov and InsideNHGRI for new recruits so they only had to memorize one URL

### Research

- Genomic Research is not labeled as being DER

### Health

- GARD missed b/c didn't know Health on HP was a link

### C&T

- link to NIH site blends in with others
- page is too busy, hard to find info
- intramural training office should be under DIR
- title mismatch – PT&CD should be education and research since that is what is on the page
- 
-

## Interview notes for B01

Thu 11/13/03

### **Take-away:**

Thinks site generally works well – but the Genetic Disorders page needs serious work

New site much better than the old site. New, pertinent info is in the center. Nav easier than it was. Search seems to work better

B1 uses R,H, P sections equally

Uses Genetic FAQ – sends it to patient advocates, also sends teachers there

Ed R – used in April when coordinating with teachers. Locates slide shows and videos there. Good that the Talking Glossary is in spanish too

Careers and Training – doesn't use (check)

Grants – uses because is ELSI research advisor. Looks at PA's. Also uses CRISP

Newsroom - uses content but typically gets there via search

Calendar of events – sometimes uses it, typically arrives there via search

### Research

Her job is coordinating 19 labs doing genetic research so she uses the Research section to see what is going on at NHGRI. Also (?) coords research about a condition her child has.

Genome Hub (0375) – uses

Genetic Disorders - doesn't use b/c there is better info on the geneticalliance page.

## Interview notes for B02

Wed 11/19/03

### Take-away:

A source for language (e.g. description of what sequencing is) & background material.  
(Health FAQs and Ed Rsrcs)

Looks over news releases

News reporter

Looking for

- current announcements/new releases
- background material

HP

- looks at lower left (New from NHGRI)
- News releases on the right

Research

- goes to Research Resources | BAC libs, Seq maps, selected journals (

Ed Rsrcs

- goes to get background materials since will be written for general public
- e.g. to get a description of sequencing

Health

- uses FAQ – can quickly look up to get language (simple sentence) to describe something

P&E

- rarely uses

Careers – never

Grants – sometimes uses

- looking for funded grants and funding history. Possibly to ferret out conflict of interests

Calls Geoff to

- set up interviews with Francis or investigators
- get detailed info on an event before it is up on the site

Uses other sources for info too (triple A's, Eureka alert) to help him sniff out timely story leads

## Interview notes for B03

Wed 11/19/03

### Take-away:

Knows the Institute but still sometimes has trouble finding info. Minority programs and opportunities very difficult to locate. .

ELSI programs and RFA's hard to find. Paths to them aren't direct. PAs for ELSI are on Fund Opps page, there is one on the RFA page. But they aren't all collected together.

### Policy

- not cross-linked to ELSI programs page (bottom left, below the fold)

10000879 – could not find (it's a report that is filed under news releases) – she had to do a search on the title (which she happened to know) to find it. That report should be findable from P&E | Discrimination | 10002977#reports – but it's not

Programs for Minorities – impossible to find through navigation. It's 10<sup>th</sup> or 11<sup>th</sup> in the search results for “minority”.

\*\*\*\*Looked for short course (done over the summer), brings in faculty from minority faculty to learn about genomics. COULD NOT FIND IT. Had to call contact within NHGRI to locate it.

April 2003 event – lovely page (1005139), but right nav cuts off because of flash (note: flash was not running on my browser). Dated materials with on-going usefulness. Those pages should continue to be available, perhaps distributed to the appropriate places. E.g. DVD, can't find, released as part of April2003 celebration, but can't find it

Newsroom – uses it to locate older information. Useful b/c info written for general public plus has relevant links. “like a mini homepage” on the topic.

\*\*\*\*Genetic Variation page “sucks”. Doesn't provide answers to

- “why is this research being done”
- “who is doing the research”
- “who is funded”.
- No mention in the initial paragraph about HAPMAP – not explanation, but then there's a link to it right below the introductory paragraph. But don't know how HAPMAP project fits in with genetic variations.

## Interview notes for B04

Tue 12/2/03

### Take-away:

Good resource to find out what kinds of questions are coming into GARD and whether some repeaters could be addressed on genome (if they aren't already)

Project manager for information center at GARD (and ORD?)

GARD provides a public service answering people's questions about genetic disorders. Their primary audience is

- families (where someone in the family has recently (?) been diagnosed with a genetic disorder)
- patients (recently (?) diagnosed with a genetic disorder)
- health professionals
- students

She uses a variety of resources to locate answers, of which genome.gov is one, to the questions and respond. If it is a phone call, sometimes she can give them appropriate URLs right then and there. If it's an email, then she composes a response. A typical day as 15 requests for information (40% phone, 60% email). Typical response time is 5-10 days for an email response. Questions tend to be unique although sometimes they overlap with previously asked questions – that's why the response takes some time, the staff needs time to track down the information if it's something new for them ("we dig in for them"). Although there are 10-15 conditions that are most frequently asked about. However, people don't always have the same questions even if the subject (the condition) gets asked about a lot. Questions about HGP get forwarded to NHGRI \*\*\*\*\* (where does that email go?) Genome.gov is just one of many resources she uses to find her answers to include in responses to queries.

Most common questions:

- How inherited
- How treated
- What research is being done on it
- Clinical studies

Some of the Health pages (e.g. some of the FAQs on certain conditions) were written by her (?) (or the GARD staff)

She will send students some of the broader descriptions of genetic research

Uses genome.gov to look up answers to policy questions

Health

- Clinical Research – sends people the URL

- Glossary – sends people the URL

#### Policy-ethics

- uses it to investigate answer to
  - o health insurance questions
  - o state legislation laws
  - o discrimination questions

General observation – sometimes hard to find things. She doesn't know the site as well as others and so must sometimes hunt around a bit. Found it a bit confusing that some See Also items stayed on site while others went off site.

\*\*\* the section on GARD is easily missed if someone takes a shortcut from the homepage because it is on the Health page, but not prominent on the pages the shortcuts lead to.



## Interview notes for B05

Wed/Fri 12/3,5/03

### Take-away:

Genetic Disorders page needs help  
Clinical Research page needs to support recruitment better  
Online Health Resources needs to expose its contents better

### 3 hats (roles)

1. currently a consultant, coordinating research for the tubular sclerosis alliance (tsalliance.org)
2. has tubular sclerosis herself
3. representative of NchPeg

### Hat 1 – coordinating research

Typically looking for information her researchers can use

- program announcements
- press releases
- funding opportunities
- conferences (these usually mostly come through NIH)

Puts out a newsletter, monthly, online that goes to researchers and clinicians. Also to sister organizations around the world (/about 12 of them).

### Policy and Ethics

- Also active on Capitol Hill, so goes here
- Also uses as a way to keep updated
- Appreciates that the Institute works with issues, not just research

### Hat 2 (patient with genetic disorder)

#### Health | Genetic Disorders

- very limited information available under Genetic Disorders
- Most important is that it feels like a dead-end, no place to keep moving forward
  - o NORD – links to a site that requests money – that may be off-putting to some people however it is a good resource and should be included. But, other free resources are missing and a newly diagnosed patient could become quite discouraged upon visiting NORD when they see that you have to pay for the reports, so other good free services should be listed prominently. Recommended resources:
    - Gene testing clinics – gives more technical information (get URL from Vicki).
    - Genetic Alliance
    - Family Voices

- Link to GARD – not prominent enough. Although it offers communication options it may not be satisfactory for many people. The text at the top doesn't clarify who they will be talking to – should say that center has “knowledgeable genetic counselors – people who will dig into a variety of resources to provide you with answers to your questions about xxx”
- Online Health Resources
  - o Top links are so general that they may lose the visitor who glances at the page to determine relevance. I.e. no diseases listed. Also, although there is a subset of diseases listed, there are no pointers to info on a wider range of conditions.
  - o *Is it possible to split that page apart into smaller sections, or to give people a better idea what is there at the top?*
  - o Link to Clinical Trials should be more prominent

#### Research

- excellent for researchers, not so good for Joe/Jane Public. *(not so sure that is a problem so long as there are links to the same info but written for public consumption)*
- Clinical Studies
  - o Nothing on the page encourages people to sign up for clinical trials. The verbiage is too bland – no sales job. Doesn't make it sound enticing. And the verbiage doesn't make it clear that these studies are recruiting – you have to deduce it by reading further down and see the “No longer recruiting” notice on some of them.
- About Clinical Research – good page, should be linked to more prominently from Health pages

#### **Hat 3 (representative of nchpeg)**

Looking for general info that might be useful for medical practitioner.

#### Ed Rsrchs

- pulls language, information, materials for presentations

#### Talking Glossary

- pulls defn's
- checks for her own edification
- pulls pictures (very occasionally)

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#### **General**

C&T – never

Newsroom - no – no time!

About

- would go here if looking for contact info, but knows NHGRI well and doesn't need to look people up very often

HP

- likes building

Doesn't see things on the right

-

## Interview notes for B06

Thu 12/4/03

### Take-away:

Power user. Knows the site, knows the material.

His organization's focus is on educating health professionals. Most health professionals have no formal exposure to genetics/genomics. He does a lot of public presentations on the subject of genetics/genomics/educating health professionals (e.g., Texas Med Society, Assoc of Medical Pediatric Chair-Persons, seminars for college students, Biology depts, genetics lab at Cinnci). Although he can reuse some material he is always seeking to have the presentations be timely and up to date and tailored to the audience.

### Ed Rsrcs

- Seeks material to use in his own public presentations or for inclusion on NCHPEG's website
  - o Slides from Francis's talks \*\*\*\*\* where are these? – gets them from Francis's staff ????
- Authored some of the content (“Exploring out Molecular Selves” & Human Genetic Variations: Curriculum Supplement:”)
- Seeks material to use in the org's educational material. E.g.,
  - o Pictures
  - o Explanations
  - o Descriptions
  - o Definitions from talking glossary
  - o Language

### Policy/ethics

- looks at this section a lot. Gets support from ELSI program, but thru the DOE
- Seeking
  - o Information on ELSI program.
  - o Report of a committee (some of which he worked on)
  - o References to papers, looking for quotations
- Uses the report section of the Discrimination & Privacy page (scrolls down to the list of reports)

### About NHGRI

- uses Staff Search – often looking for individuals
- Vision doc – looking for material for his presentations

### Health

- uses the Genetics FAQ since those are the questions he often gets when doing a presentation

-

#### Research

- Uses Products and Publications page, but gets there from Policy page
- \*\*\* he would find it useful to have this section be a searchable DB (same as A07)
- Checking for new programs and initiatives

Sometimes looking up info just to stay on top of the field. E.g., race and genetics, mental illness & genetics.

#### Grants

- occasional use
- checking program announcements when NCHPEG is asked to collaborate or write letters of recommendation or support

#### Newsroom

- rare use
- uses when looking for update talks, or keep himself generally informed

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Suggests contacting the Nat'l Assoc of Biology Teachers ([www.nabt.org](http://www.nabt.org))

## Interview notes for B07

Wed 12/17/03

### Take-away:

As an ELSI researcher she uses links from several sections of the site (Vision from HP, links from P&E, products & pubs)

Faculty, ELSI researcher, receives funding, sits on advisory committees for programs

P&E – major use “very central to what I do”

- Looks up discrimination & legislative issues
- Uses shortcuts on the left side “every single bullet is useful”, Long range planning a bit less so, but only b/c she is familiar with it
- 10001848 – good info about funds available
- pubs & products page also useful
- expects content to be NIH centric
- doesn't assume it will show relevant related activities at NCBI or NCI that would be helpful

Grants

- look at ELSI grants, looks up RFAs, but only when getting a grant ready. Finds papers to look at as prep material

Home

- thinks ELSI is only off of HP
- looks at news & new from NHGRI
- uses Vision paper

Sometimes looking for materials for other faculty, also occasionally looking up issues related to Genetics & Health.

She has “confidence in the information”

Health –

- occasionally looks at Genetic Disorders for a student or patient
- Genetest.org – 1<sup>st</sup> place for info on disorders, central, authoritative
- Her list of outside resources
  - o Genetest
  - o Genetic alliance
  - o Nchpeg
  - o NCI - PDQ – has good info for clinicians & consumers on cancer genetics
  - o CDC

10001191 – page out of date - registration for genereviews is no longer needed

Ed Rsrcs – no reason to visit, is aware it is there

C&T – no reason to visit, is aware

Breadcrumbs – didn't know how they worked

See Also – doesn't recall using it

Newsroom

- glances at it
-

## Interview notes for B08

Fri 12/19/03

### Take-away:

Power user

Extracts materials for classes, presentations to outside groups, internal tours

Peruses weekly to keep up with news, forwards top stories to everyone

Oversees outreach program at GSC (genome sequencing center) at Washington University

Uses right nav – likes that it provides info on related content

### Ed Rsrcs

- K2 and Gen ed resources- uses for in house genetic classes and ppt material for tours
- Exploring molecular selves – shows those videos
- Mentorship programs – tracking grant possibilities in there
- National DNA Day – uses those materials all the time (note these are really under About Us)
- “we use this material a lot and we love it”
- also uses Ed. Materials from DOE site

### Grants

- Funding opps – for herself, or sends link to likely person with small project, or gets sent a link by a PhD
- Grant Guidelines – not herself, but the research administrator makes much use of
- Funded grants and grant history – uses when writing grants
- Program Anncs – looks to see how could fit into those and generally have a sense of what is there
  - o Sometimes they will do the work (contract work) on a grant that somebody else writes so useful to know about these
- Minority and Special Populations
- Sometimes RFA’s are really really long. Would like headers, condensed sections, and a search function (that is more powerful than the default browser search)

### Policy & Ethics

- uses all the time, uses all of it
- pulls material for classes “all kinds of stuff”
  - o talk prep materials for outside presentations
  - o materials for in-house classes
- uses Our Genes, Our Choices material a lot
- Directs a lot of people, both from talks and classes to genome.gov

Research – rarely navs there on purpose except to the Green lab b/c his research relates to theirs

Health – not used much



C&T – more recently started to look because of outreach program

Newsroom – when big announcement comes, will ink to it from their websites. And send article to entire center (GSC)

About

- knows what is there but doesn't use it much
- except uses Long Range Planning sometimes

HP

- visits once a week to see what has popped up in the news
- and to stay up to date

## Interview notes for C01

Fri 1/19/03

*no recording, the interviewee called unexpectedly and the equipment was not set up*

### **Take-away:**

Looks at many sites – works at keeping up with scientific progress, particularly in areas he thinks are important

Survey respondent: views site very few months to keep up with what is happening.

- Looks at news
- Scans: Health, P&E, Research

Has a specific request: “I would appreciate if a matrix table including the common name\* species name\* # of chromosomes or pairs\* # of genes\* # of base pairs\* and any reference locations to get more detailed information could be presented for known sequenced plants and animals\* “

## Interview notes for C02

12/30/03

*Interviewee had no web access during the phone call, but shared his thoughts on what had seen when he looked over the site. Not recording – battery ran out!*

### **Take-away:**

Thinks current Ed. materials look a bit hard (too high level for HS bio student) but sees a lot of potential and has ideas on how to add to what is there

Molecular Genetics – if teaching this material would try using them although they look a bit above what an average HS student could do

Would like to see materials that use content on the site.

Likes having students analyze data. E.g. human genome base sequences

Raw materials is on the site but need lesson plan on top of it. E.g., DNA/Forensics games & activities

Wants ethical consideration lesson plans – what do we do with this data now that we have it?

Did tour of genome sequencing center in St. Louis but had the sense that a lot of what was talked about was “above our heads”. E.g., “library” has a whole different meaning in the field. He would have to prep kids w terminology which is extra work for teachers, makes it harder to get teachers to take it on. Also means that covering the subject takes more time. Teachers under pressure to get kids ready for state tests (which don’t include molecular genetics) so they care how long topics outside of that prep take.

Educational Resources is the right label

Helpful for teachers to attend workshops and summer programs:

- immerse them in the website so they know what is there
- have them build activities based on website
- easiest for teachers to attend when they don’t have to travel

## Interview notes for C03

1/4/04

### Take-away:

Power user – likes the site and content very useful to her

Was an intern at NHGRI - now research compliance coordinator

Tends to look at ELSI issues and Ed. Rsrcs

### ELSI

- gets to ELSI program from HP
- uses “decade of research page”
- keeps tabs on it b/c it interests her
- 

Involved in outreach. E.g., gave lecture series to health department of michigan

### Ed Rsrcs

- uses Fact Sheets E.g., Genetic Discrimination and Health insurance
  - o both as backup research for herself and when developing a list of resources to give to people
- Talking Glossary
  - o Spanish speaking one very useful

### Newsroom

- checks every few months

About NHGRI – doesn’t use, knows institute

Non-numerical URLs easier to remember

Hard to find contact info for individuals on campus

### Health

Online Health Resources – doesn’t use much b/c she already has those links  
GARD – been there once

Research – looks at investigators biographies

P&E – been to lots of left nav but not biomedical or social/cultural

Grants – only uses to get to CRISP

Uses seach 20% of the time, trys to browse first and if can’t find, then tries search.  
Site is updated regularly – that’s a plus

## Interview notes for C04

1/8/04

### Take-away:

Doesn't like the site much...too busy for her. Most of the time can find things but not always. So cluttered it seems overwhelming

ELSI – generally finds what she is looking for

### Grants

- on listserv so receives notification when no opp arrives

Would be nice to have conferences relevant to ELSI

### Health

- looks for resources to collect and distribute

\*\*\*\*\*Does not see/use R nav

### P&E

- used it to try to find who replaced Kathy Hudson (couldn't)
- uses when doing outreach

### Ed Rsrcs

- uses for outreach materials

C&T – no use

Grants – just interested in ELSI grants which she can get to off of ELSI page

Newsroom – no use

### HP

- doesn't look for news explicitly but does eyeball it
- too busy (center has 4 parts) plus top is busy
- Also Clinical Research shortcut under Health should be Clinical Research FAQ to be accurate

### About NHGRI

- PDF of org chart – 2<sup>nd</sup> page hard to fit and make big enough
  - o Shows positions but not people in the positions so not all that useful
  - o Lots of codes “HN41” “who cares”
- Text version of org chart
  - o Have to do one-by-one searching for people (*and that's ridiculous*)

Make chart show people and have it be clickable



## Interview notes for C05

1/8/04

### Take-away:

Enthusiastic about the site. Gives her good medline plus content. The site is an authoritative source. Uses it to prepare outreach materials.

Asst. Librarian at Indiana  
Also Medline Plus contractor  
Also has grant (NLM) to produce birth defects website

### Medline Plus contractor

Looks on web to locate content to put into medline content  
Submits health pages because written at consumer-level  
Issues in Genetics & Health “is really good”, Medline points to most of it  
Doesn't use Research much b/c not consumer-level

-----  
Research

- doesn't use much, but cruises to keep tabs on it

### P&E

- uses social, cultural and religious issues
- “best site as far as gathering information”

### Ed R

- e.g. giving talk to Indiana science teachers – it's a resource she can pass on to them
- “site has a lot of really nice resources”
- A link to Ed R will be on her site

### C&T

- will go in teachers part of her website and will be part of the talk for the Indiana science teachers

### Grants

- doesn't use much

Newsroom – not much, sees news through medline plus

About NHGRI – aware of but doesn't use

## Interview notes for C06

1/9/04

### Take-away:

Likes the site (good quotes below). Can find what she is looking for

Assists nurse researchers in locating opps and complete the application

Goes right for Research, doesn't look at intramural b/c not applicable (might peek in just to see if anything looks interesting)

Uses R-nav (noticed Funding opps, Funding grants & grant history on R)

A statement of funding philosophy & preferences is on most sites and she finds it is helpful to have. That was more difficult to locate on genome.gov

Did a first visit to the funded grants db and said after experimenting a bit "this is great" – i.e. she can request the info she wants and the results can be grouped in the way she wants

### Funding Opps

- looking for ELSI or C&T developemnt, or Minority Progs

NHGRI Funding Opps "this page works" "well-constructed site. I've been to some others and they are not nearly as easy"

She doesn't assume federal sites move expeired items to history page. Anything before 2000, she mails NIH to ask it is still active.

### Ed Rsrcs

- Looking for materials to assis nurse researchers. Nurse researchers are delivering info to consumers/patients

About NHGRI – doesn't use

P&E – looks to see if there is into she can pass onto nurse researchers in that area

"nicely done site, not too many distracting pictures"



## Interview notes for C07

1/9/04

### Take-away:

1<sup>st</sup> visit was during interview - useful data on Careers & Training since it is from a student perspective.

Grad student in pub health, also builds education modules for teachers in her job

Generally needs to look up facts and policy info. Often as background for her classes.

### Health

- Genetic disorders “1<sup>st</sup> para kind of long”
- Would use online health resources – “make more prominent”
- Online Health Resources – hard to read. Wants to be able to scan and not digest multiple sentences
- For diseases with a Fact Sheet, put it first since those provide good summaries

### P&E

- policy & legislation – nicely laid out
- state legislation tables “totally useful”

### Ed Rsres –

- would use in her job
- and would use summer internships for herself

### C&T

- would like breakdown by level (e.g., HS, college, grad, postdoc)
- Jobs at NHGRI – what is the difference between jobs at NHGRI and working at NHGRI?
- Jobs & Internships has resume and application info mixed in with list of jobs – it doesn't fit with the rest of the list
- PT & CD labeling issue on the page
  - o “On other sites” should be “courses at other institutions”

### Grants – never uses

Newsroom – would be looking for headlines for an email newsletter that gets sent to teachers

About NHGRI – might be look to see who was involved as well as mission & goals

\*is there info about the campus itself, were located, # of employees, etc?